‘**Growing Pains** to **Growing Shame** and **BEYOND**: *A Reflexive Dyadic on Stigmatised Identity*’.

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Signature… 

Date… 03. 05. 2018

Boy in a Dark Cupboard

"….I have always watched the birds – they soar and drift and dive – free to go where they will. Then I know; I am never going back into the cupboard – I too am going to fly".

(Anon, 1986)

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Abstract

Stigma surrounding mental health is a significant concern within the UK. Education, is considered an important aspect in attempts to address negative attitudes. This thesis opens a dyadic space in which I explore personal stigma stories relating to mental health. In addition, to consider how these connect to my doctoral journey and practice. Furthermore, how such phenomenological expression contributes pedagogically to a contemporary policy imperative; one aimed at tackling mental health stigma.

The research design is methodologically grounded in the autoethnographical method and I have developed both an 'analytical' and 'evocative' approach. Five central themes emerged from my personal stigma stories and data analysis, 'dissimilitude', 'disconnection', 'bifurcation', 'assimilation' and 'transformation'. Theoretically rich stories were then crafted, that re-presented these themes to provide further sense-making. A perspective transformative process is tightly woven within and throughout, capturing a critical pedagogic frame of reference for the inquiry.

The study adds to the existing body of literature, by contributing personal narratives in the form of stories and poetry, which may be used within my anti-stigma education. The methodological processes revealed the importance of autoethnography and its analytic reflexive potency for moving beyond a stigmatised identity. Insights gathered, enabled the development of a Model of Learning on stigma, Right Stigma Capabilities, a learning tool to be utilised in practice, and the theoretical conceptualisation of a 'Pseudo-Medicalised Identity'.

Robust mechanisms for education, continuing professional development and mentoring are required, across a multi-disciplinary health and social care context. Further research is required on the lived experience of stigma, and the generative processes involved in liberation from this complex social phenomenon.

Chapter One: Introduction, Context and Aim

Within the UK, mental health issues are extremely common. Recent policy drivers would indicate that one in four adults will experience a 'mental illness' at some point during their lifetime (Department of Health (DoH), 2011). From a governmental perspective both the social and, arguably of greater concern, the financial costs of this rising incidence of human suffering are significant. Contemporary estimates indicate the cost of this escalation to the economy at around £105 billion, much of which is accountable through "lost productivity" as well becoming an important contributor to the overall burden of disease, surpassing heart disease (DoH, 2012 p.3; Joint Commissioning Panel for Mental Health (JCPMH), 2013).

Mental health is a global issue and within the UK an urgent public health concern (Khifton and Quinn, 2013). Culture is powerful in shaping our views on how we should 'experience' emotions and respond to distress (Helman, 2007). Therefore, mental health has to be considered within its cultural context. American psychiatrist and medical anthropologist Arthur Kleinman views both clients and doctors as having different 'explanatory frameworks' that include within them beliefs about the origin of the 'illness' and the treatments that may be proffered. (Kleinman, 1988)

Thus, there are various approaches to a consideration of the topic of mental health and ill health. Mindful of this there would also appear no clear

epistemological framework for its understanding (Rogers and Pilgrim, 2014). That said the dominant model globally for "conceptualising the experience of mental distress is the bio-medical approach" (Tew 2011, p.22). However, this specialist knowledge body has been subject to much criticism, many of the seminal authorities having their roots within the 'anti-psychiatry movement', which began in the 1960s and 1970s. (Szasz, 1961; Goffman, 1987; 1990a; Foucault 1988; Scheff, 1966). These insightful and polemic thinkers challenged and continue to challenge psychiatry as a system that served to 'label' people. Similarly, they contributed to theories emerging within a more socially orientated epistemology of health and illness and came from the premise that reality is not self-evident, rather a product of human activities and in particular 'medical discourse'.

From an historical perspective it is possible to see that mental illness has been the subject of a significant body of literature in many literary varieties (Baker et al; 2010). The impact on the audience is a mixed one aimed at intrigue and curiousness over the 'unstable' reality of the 'other'. Despite the evolution of this rich and varied body of knowledge over the 'longue duree', arguably for the larger part it has been and continues to be viewed negatively, much of this conveyed through discourse, in forms such as artistic representation (Gilman, 1988) and literary tropes. Burr (1995 p.48) defines discourse as a "set of meanings, metaphors, representations, images, stories, statements and so on", that over time create a particular view of something or someone that is pervasive in shaping individual and collective perceptions and the formation of shared beliefs towards mental health (Eder, 2009).

The concept of stigma derives from Greek and refers to a mark of disgrace or shame. Mindful of the above it may then be defined as a "socially constructed negative stereotype related to the characteristics of a person" (Lester and Glasby, 2010 p.95). There exists a substantive body of knowledge on the topic of stigma (Goffman, 1987; 1990a; Mead, 1962; Szasz, 1961; Foucault, 1988; Scheff, 1966). If one adopts the lens of a historian it is possible to trace debates on this phenomenon over some considerable time. The conceptual origins have emanated from seminal writers such as Bogardus (1925) and Goffman (1990a). The former, being the pioneer of an attitudinal assessment scale focussing on 'social distance'; the latter regarded as influential in providing an ontological and epistemological framework for understanding the detrimental effects of stigma in his book entitled "Spoiled Identities". Indeed, there is a "heteroglossia" of voices past and present within the theoretical arena (Potgieter and Smit, 2009). Stigma is a universal concern (WHO, 2013).

Significantly, much of the underpinning philosophical debate has given consideration to the way societal forces influence views towards mental health. The result is the forging of both individual and collective attitudes or perceptions of normality and difference that may then lead to stigma. This socialization is influential in the way "we grow to fear anything that society calls "abnormal" (Averett and Soper, 2011 p.370). Foucault (1988) has heavily influenced theoretical debates relating to the above and the social construction of mental illness. In particular his gaze fell on notions of power and the need for the 'social control' of elements of society that did not appear to conform to the 'norms' of the day.

Kondrat and Teater (2009) consider the impact of stigma and argue that it manifests in a threefold nature, comprising stereotype, prejudice and discrimination. The effects of stigma have been shown to be far-reaching and have a profoundly negative impact on everyday life. For example, Gonzales et al. (2015) discuss some of the issues it presents for people in the workplace. Others assert its influence in connection with an individual's sense of citizenship (or lack of), which may include an impaired ability to maintain even a basic standard of living due to discrimination (Thornicroft, 2006; Faulkner 2006). With modernity comes ideas or notions of "difference, exclusion and marginalisation" (Giddens, 1991 p.6).

This public manifestation of the fear and stigma linked to mental health may also result in internalised stigma or what I would refer to as a deeply entrenched 'stigmatised identity'. Whilst there is arguably great variation in the conceptual meaning of identity, I align with Tajfel (2010) in my identification with a social group or collective. According to Corrigan (2005 in Rusch and Corrigan, 2013 p.95) this phenomenon occurs when a person turns the stigmatising attitudes inward on themselves, which may then result in how individuals think, act and behave having received a mental health diagnosis. This in turn may serve to decrease "self-esteem and self-efficacy". However, it is essential to note, the blame of this 'self-stigma' does not lie at the feet of those with 'mental illness', nor is it a clinical issue. Rather, it is a result of negative public attitudes and discrimination. (Rusch and Corrigan, 2013).

1.1 Purpose and Scope of the Study

Growing up as a child I became acutely aware of the stigma associated with this 'difference' or 'otherness'. Two of my siblings were different, one whose disabilities had them removed from society and one who existed within the parameters of what constitutes 'normal' society but was always treated differently, with fear and a sense of intolerance. Similarly, as a student of mental health nursing I saw first-hand how the attitudes of others were very negative. These attitudes were also reflected among some of the staff, there to care and provide treatment. The climate at this time did not always make for a therapeutic one.

What is poignant is a very high proportion of people in the UK hold back from disclosing a history of mental illness for fear of the detrimental impact it may then have on an individual career. Interestingly, and highly pertinent to this inquiry situated within the area of health and wellbeing, those careers that are perceived as being most at risk of damage are those in healthcare such as doctors and emergency staff (Time to Change, 2009).

Mindful of the above, the impetus for this study focus is twofold, involving a combination of both personal and professional drivers. With reference to the former, growing up with childhood experience of stigma provided an initial catalyst for my proposed study. With regards to the latter, during my mental health nurse training it very quickly became apparent that negative attitudes held by the public were also held by many of those working in a professional

healthcare role (Horsfall, Cleary and Hunt, 2010). So personal insight, along with considerable time working as an educator on stigma, places me in an ideal position to conduct research that focuses on the destructive impact and how this may be meaningfully disseminated within the teaching and learning context.

The purpose of this dissertation is to share some 'stigma stories' that relate primarily to self but are also informed by 'relational others', from a lived experiential perspective. However, these stories are situated within a much larger story that links to the title of this thesis and connects to the past, present and future in the form of autoethnography. This methodology explicitly situates self or 'myself' at the heart of the inquiry and is therefore deeply personal. I aim to connect the stories to the socio-cultural and historical context to which they belong, by doing so creating historico-cultural 'snapshots' or windows through which to view and consider stigmatised identity relative to mental health.

A further impetus for this inquiry arose from what Mezirow (2000) would refer to as *"a disorientating dilemma"* during my undertaking of the Professional Doctorate in Health and Wellbeing (Appendix 1). This growing 'unease' had been present for many years prior to this learning journey, but intensified over the first two years of study. So what made my disorientating dilemma wake up and reveal itself with such intensity? Well on reflective examination, there are several factors that contributed to this all-encompassing psychic

manifestation. Firstly, as indicated above, I had worked in the field of mental health for three decades, beginning as a nurse, then moving into education for the last 16 years with a 'specialist' focus on mental health anti-stigma pedagogy.

The commencement of the doctoral journey was a significant and pivotal moment in my life. From the outset of the course I knew my thesis topic would be linked to stigma in mental health. However in line with one of the specific learning outcomes I wanted to produce knowledge that would enhance my practice and facilitate the provision of more meaningful learning for my students. One day in class we embarked on a 'theme-board activity', which allowed for the creative engagement in a task to assemble a pictorial representation of my lived reality and experience. This is where the dilemma began to firmly take a grip and the powerful phenomenological insights revealed, ruptured a carefully contained professional identity. It opened a space for a critical self-reflection on being, at both an ontological and epistemic level, but also a deeply personal one, allowing for an intense inward gaze on self and how this self has situated and situates within an ever-changing socio-cultural and political context. Any identity of self cannot be seen as unique; rather it is "the *self as reflexively understood by the person in terms of his or her biography"* (Giddens, 1991 p.53), the process of reflection allowing for transformative process and change (Taylor, 2006).

Further to this, a review of literature sought to determine how attitudes were affected following an anti-stigma educational event. The findings of this are presented in Chapter Two and form some of the theoretical underpinning and justification for this inquiry. Stigma is an emotive topic, one that is difficult to consider due to the negative attitudes and associations attached to mental illness. I would like to highlight here one of the significant recommendations for practice that was gleaned from the review. There appeared a need for more 'contact interventions' from those with 'lived experience' as studies revealed these were more effective in initiating positive attitudinal changes (Roussy *et al.,* 2013; Michaels *et al.*, 2014). Interestingly, one study involved learning from an academic with lived experience.

This is where my existential discomfort heightened, accompanied by a greater recognition of the opportunity afforded to explore my methodological options. After much reading and cogitation, I was intuitively led to Autoethnography. It was an exciting moment, but one that was also mixed with feelings of trepidation, as the thought of revealing a long-ignored identity (a deeply personal one) within my professional practice was unsettling. It has been contended this methodological approach as part of a professional doctorate enables the joining of both the personal and professional along with its connection to rich theoretical underpinnings (Hayes and Fulton, 2015). They further assert:

"*… autoethnography can be used as a qualitative method of facilitating critical reflexivity for students undertaking a programme of study leading to the award of Professional Doctorate. Autoethnography is a therapeutic means through which Professional Doctorate students can deliberately and consciously embed themselves within theoretical perspectives and perhaps more significantly the application of these perspectives to practice*"(Hayes and Fulton, 2015 p.4).

My feelings of unease were put to one side whilst I began to expand my understanding of this relatively new methodology. This proved to be both an exhilarating and confusing time as I discovered the many different forms and styles of engaging with this genre. After many months of reading, thinking, reflecting and writing I began to feel equipped with sufficient knowledge to embark on implementing a plan. So, I hope that has enabled you to get a sense of the starting point for this research? Mezirow's (1978; 1981; 1991; 1997; 2000) theoretical insights underpin the learning journey, as I move to a state of BEYOND. Built within and throughout the inquiry are "*structures of feeling*" (Meneley and Young, 2005 p.15). These are a mix of feelings that are in a dynamic interplay with one another, whose genesis arises from a compelling belief that what I and others have to say of the lived experience of stigma is salient and current.

The thesis has also drawn on the critical pedagogy, of the late, great Educationalist Paulo Freire whose ideas have been profoundly influential in the theoretical framing of this thesis, in particular, in connection to his notion

on "*generative themes*". Freire (1972) asserts that within and throughout different epochs, ideas, values, concepts, along with hopes and fears manifest and perpetuate in a "*dialectical interaction*" with their opposites to develop a critical consciousness, in order to move towards a new understanding or concientization. In Freire's (1972) sphere this was around moving from a place of oppression to liberation in order to initiate social change and order. His ideology has been critiqued and lauded as both emancipatory and revolutionary. As an educationalist and service user of mental health, I have found his vision an inspirational guiding light allowing me to consider stigma and more importantly stigmatised identity in line with his theory.

Richards (2008) believes that autoethnography is a good match for researching and writing about illness and disability. Whilst mine is not the story of my life, nor a complete illness narrative, it does have autobiographical elements woven tightly throughout the fabric's entirety, drawing on snapshots of such to connect to the experience of stigma and how this is arguably more disabling than the illness experience itself.

The inquiry is arranged to not only address the specific aim and research questions set, but also to convey a sense of the temporal nature of reality and how this is in a continual state of flux, allowing for Freire's (1972) dynamic interplay of ideas (in this case on stigma). The structure aims to reflect the thesis title; in so doing, there are three sections that present the theoretically rich stories – '*Growing Pains, Growing Shame and BEYOND*'. There is also an intention to capture a transitional process within the cultural milieu, one that

has evolved moving *backwards and forwards* to reach a new epistemic understanding of some of the complexities of living with a stigmatised identity. The decision to capitalise this new position in the title is with the hope that there is possibility to discard some of the negative and constricting effects of stigma to wellbeing, to give meaning to the future in as much as "*I am present to it as another who I will be, in another position*" (Sartre, 1993 p.127). The process of doing this and sharing these insights with you the reader has felt risky, but necessary to become more fully authentic in practice.

1.2 Purpose of the Research

The aim of this study is directed to the telling of stories and the interweaving of these with theory in order to contribute a small narrative that engages in dialectic with what Lyotard (1984) termed the 'grand narrative'. Through the stories, address and reveal some of the existential complexities of mental health stigma. The stories will draw on my personal and professional lived experiences of stigma, informed by the insights of two siblings, to allow for the authoring of a theoretically rich text, one that is linked to the wider historical, cultural and socio-political context.

1.3 The Research Questions

The key questions that I am seeking to elucidate answers to are:

- What stories do the researcher and 'others' have to tell about the experience of mental health stigma?

- How do these stories connect to the researcher's doctoral journey, professional identity and practice, within the wider, cultural, historical and ideological discourse?

It is anticipated the stories will reveal original insights into the lived experience of mental health stigma. Within the 'ambition' of the emerging area of health humanities this thesis offers pedagogic approaches that include stories and poems that may be used within teaching and learning to provide sense or meaning making to the lived experience of stigma and how this links to my professional practice. This connection of meaning to humanities and mental health services and support enables this process (Crawford *et al.*, 2010; Crawford *et al.*, 2015). Thus, my personal narrative adds to solidifying this union within and throughout this thesis.

Furthermore, being deeply connected to my doctoral 'rite of passage' (van Gennep, 1960) and practice, I make recommendations on educational strategies that allow the opportunity in which to share these stories. Essentially, there are two main plots alongside one another, but they also meld

together, both strands forming a symbiotic union to explore their contribution to knowledge and practice.

1.4 Overview of the Study

It is important to note that in line with autoethnography, there is scope for more unconventional approaches to the research process, and as such a thesis of this nature may not look, or more importantly read, like a more conventional qualitative approach. However, this thesis has been structured in such a way to replicate to some degree the 'traditional' thesis format, which will include underpinning literature grounded in a positivistic approach, to contextualise and provide the theoretical justification for my chosen journey. It may be suggested this union of styles give possibility to reaching different audiences and interests (Richards, 2008).

Chapter Two – I will detail some of the underpinning literature that fuelled the central catalyst, paved the way and provided the backdrop for this research project. I will present some of the existing knowledge that furnishes the theoretical area and introduce some of the innovative research undertaken on anti-stigma pedagogy, along with highlighting the current gap in knowledge that I aim to contribute towards.

Chapter Three – I have made reference to the methodology within this introduction. However, within this section, I intend to provide detailed

justification along with how this choice would appear most appropriate to address the research aim and questions. Consideration will be given to philosophical concerns along with discussing, describing and debating my ontological and epistemological foundations. In addition explicate how these connect to my own researcher positionality in the context of perspective transformation and this inquiry. The gaze will then focus on defining autoethnography, provide some of the historical background and critiques of the methodology, with linkage to theoretical understanding and the visions of seminal thinkers in the field. It will then move to offer a detailed explication of the methods and processes that have formed the building blocks of this study, along with some of the challenges that I have experienced along the way. The aforementioned included much contemplation of unique ethical considerations and this has been ongoing throughout the project. Finally, this chapter will detail the data sources, collection and interpretive processes and examine salient evaluative criteria (Table 3.3) used for this genre of research.

Chapter Four – I present the findings in a storied format, under the thesis title which aims to capture within the stories a reflexive dyadic thread of conversation. Dyadic is defined as "interaction between two people" (Cambridge Dictionary, 2017) and in this inquiry moves between self and significant others. Interspersed throughout the narrative are both poems and photographs. I am no expert in the art of poetry; however, the ones included emerged quite spontaneously and perhaps cathartically and may have potency for expanding the lived experience alongside the theoretical underpinnings (Grant, 2016b). For me personally, the writing of these were what I would

refer to as emotive catalysts, that in themselves provided a mechanism to move BEYOND, as well as address the specific research questions. Similarly, the pictures included have purposely not been labelled or given any meaningful discussion. It is anticipated, as with the poems, that the visual imagery considered alongside the text may provide a resonance for the reader's own meaning making (Turner, 2012). The stories will be followed with theoretical linkage to illuminate the themes.

Chapter Five – Within this section, I will draw the threads of the narrative fabric together and consider some of the challenges of this study, along with presenting some of the methodological limitations. In addition I will link back to the literature that formed the impetus for the inquiry. I unashamedly present a reflective self-focussed dialogue, on what I believe are the strengths of the methodology and the capacity to address the research questions in both a creative and analytical way.

Chapter Six- Finally, I will discuss the original contribution to knowledge that has evolved and an overview of what has been achieved, with particular consideration of the most salient elements of the study which are the stigma stories. I will then move to make specific recommendations for mental health pedagogy and how the findings revealed will inform and influence my practice, along with ideas for future research studies in this important area of mental health.

This chapter has attempted to present the justification for this research inquiry, along with its salience within contemporary society and my professional practice. I have begun to allude to some of the deeply personal motivations and will reveal these in greater depth as the thesis unfolds. The next chapter continues the story, giving detail to the research literature that sealed the impetus for the journey.

Chapter Two: Review of Background Literature Review

This aim herewith is to present a review of selected literature which formed the foundation for my rationale, along with the justification underpinning my decision to conduct an autoethnographical inquiry on my lived experience of stigma. Firstly, I will begin by discussing some relevant and current anti-stigma pedagogical research. Secondly, move to consider both the strengths and perhaps more importantly the limitations in this body of knowledge. Finally, to suggest how I anticipate this study may extend this knowledge further through addressing my specific research questions.

2.1 Introduction

First, the phenomenon of stigma in mental health has attracted attention of researchers, clinicians, politicians, educators and service users at national and international level (Goffman, 1990a; Rusch, Angermeyer and Corrigan, 2005; McAllister, 2008; Time to Change, 2008; 2009; Grant, Biley and Walker, 2011; Yamaguchi, Mino and Uddin, 2011; Department of Health, 2004; 2011; 2012; WHO, 2001; 2014; Grant, 2014a; Grant and Leigh-Phippard, 2014). The contemporary context suggests compelling evidence indicating the need to acknowledge the profound impact of stigma through the life-course. This should undoubtedly include extension to those living with dementia. From a historical perspective mental health has undergone significant shifts in thought relative to attitudes, care and treatment, but as previously indicated the uniting thread is that in the main attitudes have remained negative (Macdonald, 1983; Scull, 1982; Showalter, 1987; Foucault, 1988; Porter, 1998).

One compelling force in this continuity is arguably the institution that is psychiatry, that rather than conveying restorative qualities is 'potentially' oppressive and stunting, which in turn may lead to temporal discontinuity of lived experience (Giddens, 1991). Furthermore, a work environment that is governed by bureaucracy and overworked staff is arguably less favourable for harnessing and nurturing the capacity for compassion (Crawford *et al.,* 2014) and mutually beneficial relationships (Brown, 2016). However, within the wider society it would appear attitudes are now becoming more favourable (TNS UK, 2014; Mental Health Taskforce, 2016).

DoH (2012) cited one of six objectives, as the aim to raise awareness and take steps to reduce stigma. Similarly, the 'voice' and involvement of service users and carers is now a central priority for service delivery, research and education within the arena of Health and Social Care (Gray, 2006; Wallcraft, Schrank and Amering 2009; Leiba, 2010; Weinstein, 2010). Drivers such as The Expert Patient (DoH, 2001) provided a catalyst for this involvement in all elements of care which included the planning and delivery of services (Crawford *et al*., 2003). However, some would argue there is still significant societal discrimination (Gray, 2006; Thornicroft et al., 2009) and much work to be done (Lakeman, Walsh and McGowan, 2007).

In order to provide some context and background to my journey an initial literature review was undertaken forming the impetus for an inquiry of self. The aim was to identify the effects of educational interventions on the perceptions of 'healthcare-related' undergraduate students towards people

with mental-illness, following an anti-stigma educational intervention. Coughlan, Ryan and Cronin (2013 p.1) determine the importance of a literature review and it's centrality to the process of research. They further contend its relevance for providing opportunity to critically appraise the quality of the existing body of knowledge and enable contextualization and specific focus to a given topic.

The review examined a combination of peer-reviewed primary research, along with legislative directives and grey literature in relation to anti-stigma pedagogy which included learning from those with mental health lived experience. Furthermore, it aimed to highlight the current policy context on stigma pedagogy. An overview of the studies can be located in Appendix 2**.** The purpose of the review was to determine any possible gap in knowledge, in order to provide justification for my anticipated doctoral research.

The time frame for the review was 2004-17. The justification for this was influenced by my professional experience, along with what would appear to be a more visible presence of anti-stigma discourse via academic research, policy initiatives and the more generic national and international campaigns cited above. From a pedagogical perspective, education has been identified as a 'critical' element in this endeavour (Rusch, Angermeyer and Corrigan 2005; McAllister, 2008; Yamaguchi, Mino and Uddin, 2011; Grant, 2015). Many contend the need for a 'range' of creative educational approaches that are aimed at enabling students to consider the topic of mental health, and have the opportunity to examine existing attitudes and perceptions (Crawford *et al.,* 2010; Yamaguchi, Mino and Uddin, 2011; Grant, Biley and Walker 2011;

Crawford *et al.*, 2013; Grant, 2014a; Grant and Leigh-Phippard, 2014; Crawford *et al* 2015; Grant, 2015a; Grant, 2016b). Similarly, there have been attempts to understand the negative attitudes that are harboured by students (Madden, Aguiniga and Zellmann, 2014) along with the impact these attitudes may have on thinking and behaviour (Szeto, Luong and Dobson, 2013). Mindful of this, stigmatising attitudes have been highlighted as a concern among health care professionals (Horsfall, Cleary and Hunt, 2010, Roussy *et al.,* 2013).

Research suggests these negative attitudes may lead to 'subtle' communications which on both a verbal and behavioural level convey negativity that has the potency to impact on treatment (Pierce, 1989; Sue, 2007; Gonzales *et al.*, 2015). In line with transformative learning theory, the danger is these attitudes risk becoming 'habits' of mind (Mezirow, 1997). Arguably, stigma and a stigmatised identity is a habit of mind, one which results in a complex mix of feelings, attitudes, perceptions and judgments either towards self or those with 'mental illness'.

It would appear to be a salient time for innovative learning opportunities that provide opportunity and space for what Mezirow (1978; 1981; 1991; 1997; 2000) would term as "*perspective transformation*". One that initiates a change in individual and collective 'frames of reference' towards mental illness. As Freire (1972) has asserted it is only through gaining a full understanding of a particular 'reality' (in this case stigma) that one can move towards liberation. This is further supported by some compelling evidence for the inclusion and

recognition of a 'social model' within mental health care (Tew, 2005; 2011; Rogers and Pilgrim, 2014), as well as the introduction of a 'human paradigm' (Grant, 2015a).

2.2 Literature Search Criteria

For the purpose of this literature review, it is important to provide some justification on the use of terminology. Therefore, attitudes are defined as "*a psychological tendency that is expressed by evaluating particular issue in a positive or negative way*" (Lester and Glasby, 2010 p.95). The use of the term mental illness is not one that sits comfortably here, but it has been adopted throughout and refers to what would be considered a range of psychological conditions that are given a diagnostic label (and are often widely referred to as mental illness). Arguably, I would suggest this term may serve to heighten and perpetuate stigma. The decision to use it here is because it would appear to be the preferred term within the literature, and other search terms utilised (that are arguably more neutral and less bio-medically framed) were not as fruitful when conducting the search.

An electronic search was conducted, seeking peer-reviewed articles in the public domain. The databases used were CINHAL, Eric, Educational Research Complete, Medline, psychINFO and SocIndex. These repositories were deemed the most appropriate for the topic of inquiry, which is an important consideration (Fink, 2013). The search terms used were *undergraduate, attitudes or perceptions, mental illness, education, stigma and students*.

Additionally, time was devoted to a manual examination of the reference lists and bibliographies.

2.3 Overview of the Studies

The research identified studies that all appeared to focus on the role of mental health anti-stigma education and the impact this had on student attitudes. The selected works were eclectic, revealing a variety of methodological approaches, although interestingly the majority were of a quantitative design (Mann and Himelein, 2008; Happell *et al.*, 2014; Wood and Wahl, 2006; Altindag *et al.*, 2006; Galletly and Burton, 2011; Economou *et al.*,2012; Friedrich *et al.*, 2013; Poreddi, *et al.*, 2015; Bannatyne and Stapleton, 2015; Muzyk *et al* 2017). Three of these studies were Randomised Control Trials (Roberts, Wiskin and Roalfe 2008; Clement *et al.*, 2012; Kassam *et al.*, 2013; Burns *et al.*, 2017), and the rest used qualitative inquiry to determine the impact of education on student attitudes. (Bryne *et al.*, 2013; Bizub and Davidson, 2011; O'Reilly, Bell and Chen, 2012; Matteo, 2013; Bharathy, Foo and Russell, 2016). The collective works adopted an international perspective. The countries of origin where most of the research had been conducted was both Australia (n = 6) and the USA (n = 5), then the UK (n = 3), Turkey (n = 1), Greece (n = 1), Malaysia (n = 1), India (n = 1) and Canada (n = 1).

Significantly, all of the studies were conducted within a higher education learning context which is relevant to myself as a lecturer situated within this environment. The majority of papers focussed on mental illness generally

whilst three had a focus on the specific mental illness, 'schizophrenia' (Economou *et al*., 2012; Galletly and Burton, 2011; Altindag *et al*., 2006) and one on 'Anorexia Nervosa' (Bannatyne and Stapleton, 2015), the latter being particularly pertinent to this study for reasons that will become apparent later. Research participants comprised healthcare related undergraduate students, who were all on what appeared to be vocationally-orientated courses, which included nursing, medicine, psychology and pharmacy. However, one of the studies involved students on a common foundation programme related to psychology topics (Wood and Wahl, 2006).

The researchers who conducted the selected studies utilised a range of educational interventions, which included traditional teaching methods (lectures etc. with a bio-medically framed focus) (Altindag *et al*; 2006; Happell *et al.,* 2014; Poreddi *et al.,* 2015; Bannatyne and Stapleton, 2015; Burns *et al*., 2017; Muzyk *et al.,* 2017), reading from first person narratives of mental illness and role play (Fredrich *et al*; 2013), placements (Economou *et al.,* 2012; Bharathy, Foo and Russell, 2016) and finally contact-based sessions (live/DVD) (Wood and Wahl, 2006; Bryne *et al.,* 2013; Kassam *et al*; 2013; Matteo, 2013; Happell *et al*; 2014; Bharathy, Foo and Russell, 2016).

Further to this, the dominant design adopted among all the papers involved the implementation of a pre- and post-intervention questionnaire to collect the data (n=13). The follow-up period varied from one to six months and the pre- and post- intervention response rates for those who identified such within

their studies were variable. The length of the interventions across the studies also revealed notable variability, the shortest being a one-off single high-intensity role play followed by a 40-minute discussion (Roberts, Wiskin and Roalfe, 2008) to a programme lasting 12 weeks in duration (Happell *et al.*, 2014).

Within the selected papers, the evaluation of attitudes was collected using a variety of tools, some already validated and established for the gathering of evidence. For example in one of the studies by Clement *et al.* (2013) four different measures were employed, one specifically related to attitudes using the Mental Illness: Clinicians Attitudes Scale (MICA). In particular some studies utilised the Social Distance Scale (SDS) which measures attitudes to a range of factors, such as behaviours to avoid contact with someone with mental illness (Wood and Wahl, 2006; Roberts, Wiskin and Roalfe, 2008; Economou *et al.*, 2012; Burns *et al.*, 2017). However, some developed and adapted instruments specific to their project (Altindag *et al.*, 2006; Wood and Wahl, 2006; Mann and Himelein, 2008; Happell *et al.*, 2014; Boucher and Campbell, 2014; Bannatyne and Stapleton, 2015).

One study incorporated the 'Jefferson Scale of Physician Empathy' (Friedrich *et al.*, 2012). This included a series of empathy-related statements, which enabled the participants to consider factors such as having awareness of a client's emotions and emotional ties and the importance of the latter for recovery. It is important to note here the instrument is arguably not an

attitudinal measurement tool. However, empathy is considered a 'quality' and an essential one for healthcare workers to cultivate. The decision to include it here is because it is deemed a valuable element for the development or nurturing of humane attitudes conducive to wellbeing.

2.4 Review Findings

Moving then to consider and interpret the results of this critical review. The analysis and synthesis adopted a thematic content approach that was inductive in nature and allowed for the identification of broad themes (and sub themes in some instances) through highlighting relevant strands within the individual papers (Denscombe, 2003; Aveyard, 2014). The intention was "*to produce a new and integrative interpretation of the findings that are more substantive than those resulting from individual investigation*" (Fingheld, 2003 p.894), in addition allowing for the development of direction for this inquiry. As a result of the above the following themes were identified*: A positive re-evaluation of attitudes towards mental illness; Empathic learning spaces for perspective transformation*; *Opinions of the educational event*. These will now be explored in more detail.

2.4.1 A Positive Re-evaluation of Attitudes Towards Mental Illness:

Overwhelmingly, the majority of the studies' outcomes suggest a positive attitudinal change among the varied student bodies involved (*n*=16*)*. Conversely, some papers indicated no significant impact on student attitudes

following the intervention (*n*=3). Within the selected timescale for this review, the earliest study, by Altindag *et al.* (2006) surveyed medical students' attitudes towards the specific mental illness 'schizophrenia', within their first year of training. The purpose of the study was to determine whether such an intervention would influence students' attitudes. The study suggests slight positive changes were apparent to areas such as social distance, but appeared to decline at a one-month follow up.

Matteo (2013), conducted an exploratory study with undergraduate psychology students in three introductory psychology classes. The test carried out prior to the intervention indicated negative associations with mental illness and most notably students indicated that these ways of thinking were instilled and nurtured at school. One student spoke of their memories of some of their peers with mental health problems being segregated within the institution and subjected to ridicule and discrimination. Post-intervention findings highlighted changes in attitudes relating to a number of areas, although perceived ideas relating to the attributions of someone with mental illness elicited the most responses.

Bizub and Davidson (2011), employed contact interventions in a qualitative study involving undergraduate psychology students. This entailed students befriending someone with lived experience of mental illness. Despite a relatively small sample size, some important findings were revealed, that indicated a positive effect on respondents' attitudes. Pre-test attitudes

indicated some trepidation and anxiety, particularly in relation to the notion of 'unpredictability' and fear of exposure to aggression. Post-test, one student expressed feelings of guilt for this negativity and how these feelings led to more of an awareness of 'positive qualities'. The experience provided opportunity to reflect on attitudes, which at times students acknowledged was challenging. O'Reilly, Bell and Chen (2012) explored the views of 11 pharmacy students and 12 Mental Health Consumer Educators. This co-operative approach with students and service users sought to determine the self-reported effects of service user led education on attitudes. In line with the above, this study revealed attitudinal improvements, which they asserted then led to behavioural changes. Finally, Bharathy, Foo and Russell (2016) involved an eight-week placement within a non-governmental organisation where medical students interacted on an equal basis with service users through a 'chat and connect programme'. The results again indicated some beneficial effects.

In contrast Economou *et al.* (2012) determined that the educational approach taken in their study had a negative effect on the attitudes of medical students towards the mental health condition schizophrenia. As with some other studies, the researchers sought to explore the sample populations' attitudes and beliefs about this condition before a placement in a psychiatric setting and again following this experience. Interestingly, the findings appeared to reveal that the placement did not influence attitudes and seemed to show a negative impact on attitudes. Similarly, Roberts *et al.* (2008) provides some

contradictory evidence with no marked difference in attitudinal change. Here, unlike the other, the focus of training centred on an individual one-off session.

The randomised control study by Roberts, Wiskin and Roalfe (2008) sought to establish whether role-play activities that involved a mental illness scenario had an impact on attitudinal change. Findings suggested that there was no notable difference between either the control or intervention group. However, there was some indication of positive changes to overall stigma scores. Clearly, it may be gleaned that the studies that were framed bio-medically were not very impactful on changing attitudes (Boucher and Campbell, 2014; Muzyk *et al.,* 2017). Therefore, study design is also an important factor to be mindful of. Furthermore, statistically-orientated studies may reveal a strength of validity, but, unlike the qualitative studies, lack depth for elucidating meaning on the nature of attitudes and there was no lasting change or evidence of perspective transformation.

2.4.2 Pre-conceived Ideas

In the study by Matteo (2013) pre-intervention attitudes on the attributions of mental illness generated feelings of sadness and pity among the participants. Similarly, Bizub and Davidson (2011) identified perceptions linked to ideas of dangerousness and aggression, along with fear that instilled a sense of apprehension at the start of the study and a concern for general safety. However, results post intervention indicated a positive change. This theme was developed further within some of the other studies reviewed (Friedrich *et*

al., 2013; O'Reilly, Bell and Chen, 2012; Mann and Himelein, 2008; Kassam *et al*., 2013; Poreddi *et al.*, 2015; Bharathy, Foo and Russell 2016; Burns *et al*., 2017; Muzyk *et al.,* 2017), clearly indicating the benefit of training to change notions of 'dangerousness' associated with mental illness.

2.4.3 Stigma and Discrimination

Linked to pre-conceived ideas the whole issue of stigma and discrimination was a significant focus in some of the studies (Altindag *et al*., 2006; Bizub and Davidson, 2011, Mann and Himelein, 2008; O'Reilly, Bell and Chen, 2012; Bannatyne and Stapleton, 2015; Poreddi *et al.,* 2015). Relative to this, all the participants in the investigation by O'Reilly, Bell and Chen (2012) reported a change in attitudes associated with the above theme, along with a more optimistic view towards mental illness. Bizub and Davidson (2011) highlighted how the students felt the event afforded opportunity to learn about the full impact of stigma and discrimination, in particular surrounding the 'de-humanising' effect negative attitudes convey.

The study by Bannatyne and Stapleton (2015) directs the spotlight on the eating disorder Anorexia Nervosa and suggests that stigmatising attitudes towards this group are particularly alarming. They refer to 'volitional stigma', with attitudes that victim blame sufferers for their 'self-inflicted', vanity-fuelled condition. Despite such negativity levelled against this group the training did appear to provide some cautious evidence that 'brief targeted interventions' may reduce stigma. Further to this Matteo (2013) indicated that

students' engagement with the educational activity provided a catalyst and safe space for self-disclosure around their own personal experiences of mental ill health. Overall, it would appear that these studies facilitated greater participant insight into the experience of mental illness; as one student indicated in the study by O'Reilly, Bell and Chen (2012 p.610) it "pushed my comfort zone and I had to re-evaluate".

2.4.4 Attitudes Towards Social Distance

Results from the research by Altindag *et al.* (2006) showed improvement in attitudes relating to social distance. Notably more of the sample in the intervention group showed a positive shift post event, particularly in relation to items such as 'accept as co-workers', 'as neighbours' and 'aggressiveness of patients. Other studies revealed similar findings (Kassam *et al.,* 2013; Wood and Wahl, 2006; Burns *et al.,* 2017). However the psychiatric placement undertaken by the participants in the study by Economou *et al.* (2012) appeared to heighten stigmatising attitudes, this being notably prominent in relation to beliefs about 'dangerousness'. Variables relating to gender seemed to have some bearing here; interestingly female participants seemed to harbour more negative attitudes. It is worth noting that the study by Poreddi *et al.* (2015) revealed the opposite that the female participants were less likely to be stigmatising. The latter potentially risked bias as group characteristics revealed a higher percentage of participants were female. As the studies were conducted across different countries it may be that culture has an influence on this issue.

2.4.5 Empathic Learning Spaces for Perspective Transformation

From the perspective of transformational change, Bizub and Davidson (2011) found that providing psychology students with opportunity to have contact with consumers, to be able to talk and listen to their experiences brought about a new realization. This involved the letting go of initial fears they may have harboured and recognition they were indeed unwarranted. This insight served to heighten self-awareness, knowledge and empathy for those living with mental illness.

Interestingly, there appeared to be a shift in attitudes that associate mental illness with a sense of hopelessness and danger, to notions of resilience and a heightened feeling of optimism. Importantly the interventions appeared to provide a catalyst for a more informed insight and understanding towards mental illness. Others have also identified this perspective change in their students (O'Reilly, Bell and Chen, 2012; Bryne *et al*., 2013; Friedrich *et al.,* 2013; Clement *et al*., 2012; Muzyk *et al*., 2017) in particular, having the space to challenge their pre-existing ideas and perceptions, along with the opportunity for reflection and change (Bryne *et al*., 2013) and greater empathic responses (Friedrich *et al*., 2013). A further advantage identified by the participants in the study by Bryne *et al.* (2013) was that emanating from an epistemic awareness was a recognition of the need to change current practice to one that embodied a more multi-layered and mindful approach with an emphasis on the nature and centrality of the therapeutic relationship.

In the study conducted by Matteo (2013) the event led to the self-disclosure of some of the students, who felt able to share their own personal stories of mental illness. This enabled greater self-awareness (empathic awareness). This finding was revealed in three of the other studies, where students felt this change in understanding initiated the formation of new insights (Bizub and Davidson, 2011; Bryne *et al*., 2013; Muzyk *et al*., 2017). O'Reilly, Bell and Chen (2012) revealed students found the learning to be an emotional experience, one that then enabled the transformation of attitudes and a more positive reorientation. It was felt these new insights led to changes in behaviour and as one student stated, it was like seeing through "*fresh eyes*" post-intervention (Bryne *et al.*, 2013 p.198).

Clearly, the above supports the contention that anti-stigma pedagogy involving 'lived experience' has the potential to act as a catalyst for what would be described as 'transformative learning', and for learners to develop greater levels of 'criticality' and deeper reflectivity, which in turn may trigger a change in their 'frame of reference' (Mezirow, 2000). Some of these studies support the importance of dialogue for inducing 'empathic resonance' or 'felt' learning to move our thinking forward.

2.4.6 Opinions of the Educational Event

As indicated above, the findings here strongly suggest that the most significant changes in attitudes occurred when students heard from those with lived experience of mental health. Bryne *et al*. (2013) found an emergent theme

in their study centred very much on the teaching, which was delivered by an academic with lived experience of mental illness. Despite some participants expressing initial surprise, the majority found that having the opportunity to understand this way was powerful in seeing through a 'new lens' and provided for a deeper learning experience. Further studies also concluded that this type of contact is a favourable pedagogy to adopt, particularly when planning educational research and practice for future generations of healthcare-related professions (O'Reilly, Bell and Chen, 2012; Bryne *et al.,* 2013; Poreddi *et al.*, 2015). It is acknowledged by the former that exactly how contact has this effect lacks clarity, but they determine its importance in challenging myths and stereotypical perceptions relating to mental health and for providing a catalyst for becoming actively engaged with the learning.

In line with the above theme the more statistically-framed study by Clement *et al.* (2012) revealed some of the participants' views on process variables. Students who received training via a DVD reported a greater emotional response compared to those who were given a live session. Similarly, students who obtained a combination of learning from both live and DVD had a greater emotional reaction than those who participated in a more formal lecture setting. In the randomised controlled trial conducted by Kassam *et al.* (2013) findings examined the respondents' evaluation of the course and its teaching methods. Medical students' perceptions of the course were measured along with the perceived impact on attitudes and behaviours. In the main, contact-based approaches were deemed to be the most effective. This has correlations with some of the findings linked to providing opportunity for emotive learning

that enables students to examine their internal frame of reference relating to people with mental illness and the development of greater empathy. There were some contradictions as previously indicated, as the study by Economou *et al*. (2012) included contact but this only served to intensify negative attitudes.

2.4.7 Temporality

Student attitudes in the majority of the studies supported the effectiveness of an anti-stigma educational intervention. This appeared to be particularly significant for their measured attitudes, taken immediately following the training event. Again the study by Economou *et al*. (2012) included a placement that ensured contact with service users and, despite this, results appeared disappointing. One of the reasons for this was that many had placements within acute mental health settings, where clients were reported to have had greater levels of distress, which it is suggested influenced negative attitudes regarding the possibility of recovery, but also students' attitudes and perceptions associated with dangerousness and unpredictability which propagated more pessimistic ideas relating to recovery. Interestingly, further findings from some of the studies appear to reveal that positive changes do not last, as attitudes measured following a time interval yielded a decline (Altindag *et al*., 2006; Friedrich *et al*., 2013). The consideration of temporal issues relating to the educational event is also considered in the study by Roberts, Wiskin and Roalfe (2008) who indicated single education sessions did not appear to influence student attitudes. Whilst acknowledging the changes

in attitudes, the long term implications for change need to be considered (Bharathy, Foo and Russell, 2016; Burns et al., 2017).

2.5 Review Implications

The papers selected for review reveal in the main positive attitudinal changes. This would appear to indicate that education is a critical component in reducing the stigma associated with mental ill health. Evidence was further yielded on the nature of the intervention, suggesting that certain forms such as 'contact' tend to be more effective in influencing attitudinal change amongst students. Clearly, this carries important implications for those involved in the planning and development of research and pedagogical initiatives aiming to contribute to this international imperative to address stigma. There is an ongoing need to fully appreciate and understand the mechanisms and conditions required to garner long lasting change.

Similarly, there would appear to be a need for further work centred on sustainable pedagogy. The research presents some interesting findings regarding the temporal nature of the educational event and the impact this has on any long term attitudinal change. Educational approaches that include work on critical self-awareness are valuable elements for providing opportunity to challenge existing ideas and attitudes (Freire, 1972; Mezirow, 2000).

In line with temporal considerations, many of the studies did not carry out any long term follow up, only pre-post-test assessment. Therefore, more studies that address the long term effects would appear to be necessary. Consideration is required on the ongoing nature of such change and how this is both translated and sustained relative to both knowledge and practice improvements.

Furthermore, others have stated that for any anti-stigma teaching to be successful it needs to address 'power issues' (Grant, 2015a; Brown, 2015), for example, the attitudes of dominant groups such as doctors and psychiatrists. Evidence appears to indicate such professionals hold greater stigmatising attitudes which become more deeply ingrained with experience, and then arguably more resistant to change (Knapp *et al.,* 2007). As previously acknowledged, one of the studies highlighted that medics' attitudes towards mental illness became more negative after time in practice (Economou *et al*., 2012). In addition attitudes to Anorexia Nervosa were particularly hostile (Bannatyne and Stapelton, 2015). Indeed, these negative opinions may affect the therapeutic encounter, outcomes and the self-esteem of the client (Gonzales, *et al.,* 2015; Brown, 2016).

The results appear to indicate that traditional mental health courses underpinned by a bio-medical perspective have less impact on attitude change (Boucher and Campbell, 2014; Muzyk *et al.,* 2017). With this in mind, curriculum developments need to draw on this emerging evidence base surrounding anti-stigma pedagogy. As an educationalist situated within

higher education and whose student body would fall into 'healthcare-related' undergraduates, the above are salient issues to take note of and develop further, in line with policy directives. As highlighted by a relatively recent narrative review and further supported by the results of this paper, direct contact with service users living with mental illness appears to be the most compelling educational method for reducing stigma (Yamaguchi, Mino and Uddin, 2011).

The studies reviewed have collectively made a significant offering to the body of knowledge and evidence supporting the role and more importantly the nature of education for changing attitudes and perceptions. This provides testimony for the need for further studies to develop and enhance understanding of the topic. The ones included here do appear to present some compelling evidence for positive attitudinal changes, if not the detail on some of the dynamics within the educational experience that influenced this.

Mindful of one of the doctoral learning outcomes, a central imperative was to demonstrate a systematic approach to reviewing the literature to address my research questions. Interestingly, the search revealed the majority of literature was weighted towards a quantitative stance, with little qualitative data. Indeed, from a philosophical perspective research grounded in a positivist paradigm is diametrically opposed to autoethnography. However, a synthesis of both quantitiative and qualitative research revealed the potential of education to impact on student attitudes. Furthermore, the analysis highlighted a distinct gap for more qualitative studies that involved learning

from lived experience and in particular giving consideration to the nature of attitudes. The review was a powerful factor in the fuelling of my disorientating dilemma as well as forming part of the underpinning theoretical framework for this autoethnography. One designed to share with you my stigma story and transition through a critical transformative process on the doctoral passage to move to a new position in my practice.

Thus, to reiterate as indicated above the body of evidence reviewed is weighted towards experimental design, with only five of the studies adopting an exploratory methodology. I would suggest this may be due to some of the difficulties associated with discussing mental health issues. The continued use of both experimental and descriptive research on this topic is therefore likely to continue. These types of study are often ones that gain funding. As can be seen, design that allows for the generation of theory may be powerful for elucidating greater understanding of perceptions, along with the ability to capture individual and collective views. Such studies as the ones reviewed here have more recently contributed towards the much needed depth of knowledge that would appear to be required for this ongoing endeavour (Matteo, 2013; O'Reilly, Bell and Chen, 2012; Bizub and Davidson, 2011; Bryne *et al.,* 2013; Bharathy, Foo and Russell, 2016).

Furthermore, there is compelling evidence to strongly support the involvement of consumers within the educational processes (Repper and Breeze, 2007; Terry, 2012; Roussy *et al.,* 2013; Michaels *et al.,* 2014), to build on studies that have revealed the positive role of service users in the training of vocational

courses such as nursing (Rush, 2008; Blackhall and Shafer, 2012). Studies within the higher education context would indicate that learning from those with lived experience of mental ill health is more powerful for transforming learner perceptions towards mental health (Bizub and Davidson, 2011; O'Reilly, Bell and Chen, 2012; Bryne *et al*., 2013; Matteo, 2013; Bharathy, Foo and Russell, 2016). Therefore, further lines of inquiry that allow for a synergy of both professional knowledge and experience of service users could be just as important for understanding reality as other forms of research (Glasby and Beresford, 2006). This has been acknowledged as a recognised way forward by professional bodies concerned with standards for education, for example the Nursing and Midwifery Council (2010) as well as their valuable contribution to research (Wallcraft, Schrank and Amering 2009).

In line with notions of lifelong learning, education is viewed as a process as opposed to isolated or disconnected events. Matteo (2013 p.241) also refers to the importance of stigma reduction to be thought of as "*a social development process*". This echoes some of the ideas embedded within the mental health recovery literature that relate to notions of process and journey, that may mean taking steps back to move forward (Gray, 2006). The implementation of mentoring and supervision that is integral to ongoing education and practice may enable students in a supportive context to make the transition from graduation to the workplace and contribute to the sustainability of positive attitudes. This may be an important area for greater mental health service user involvement in working alongside providers.

There is a call for ongoing research that involves a range of healthcare-related staff, including non-vocational courses, for example Health and Social Care students, who go on to gain employment in a variety of roles, many in the voluntary or independent sector. This review has drawn on what may be considered a strong hierarchy of evidence (Aveyard, 2014; Greenhalgh, 2014), therefore supporting the importance of ongoing high quality studies. However, to determine in-depth and detail the experience that led to change there is a need for further lines of inquiry that adopt a qualitative methodological approach (Brohan *et al.,* 2010).

There would appear to be a paucity of qualitative literature pertaining to the actuality of the stigma experience. That said, there are academics who have pioneered the way forward, particularly on their lived experience of mental illness (Deegan, 1997; Grant, 2006; Short, 2010; Grant, Biley and Walker, 2011; Grant, 2011; Glover, 2012; Grant, 2014a; Grant, Leigh-Phippard and Short, 2015; Grant, 2015a; Grant, 2016c), but as supported by the literature review and above authors, more sustained work is required. The national anti-stigma campaign, 'Time to Change', has a visible presence, in the main drawing on the lived experience of celebrities and people who hold prominent public personas. Perhaps it is time for me to change. I sit in the classroom and in many ways hide behind a façade, one that presents as the academic with the specialist theoretical knowledge, but on the side a rising tension in the need to be fully congruent in practice.

I involve service users in my learning, who like me have lived experience of mental health issues (but mine are not talked about, there is a distinct separation). The students' evaluations of such input are always overwhelmingly positive and would suggest that for some there is a perspective transformation (or deep learning) in their thinking around the topic and their perceptions of someone living with a mental health issue. I am an educator of stigma: committed to delivering teaching and learning that aims to foster space for students to reflect on their attitudes to mental health. The literature review has revealed a need for more qualitative studies focussed on the learning from contact interventions. Therefore, this autoethnography aims to reveal the lived experience of stigma by sharing my story. I would like to capture some personal stories of stigma on the nature of the lived reality within this inquiry that may be then used in my practice in higher education.

A limitation worth mentioning is that this critical literature review included only published peer-reviewed journal articles in English and also only studies available in full text within the cited databases used. It is possible there is other research that attempts to capture the impact of education on mental illness stigma that I have overlooked.

Clearly, the topic presents as an emotive issue, one that for many is difficult to consider, let alone disclose, as it is deeply associated with negative attitudes and pre-conceived ideas. This may be a significant factor contributing to the apparent historical resistance to change. Furthermore, some have questioned

whether it is possible to dispel these deeply-entrenched notions and challenge the epistemic roots of stigma discourse (Porter, 1998).

Smith (2014), Vice Chair of the International Mental Health Collaborating Network expresses his discomfort with the use of the term stigma. He argues that by its very usage we actually buy into the conception that is being questioned. Language is powerful! Language is harmful. Certainly, I agree with his debate on power and the damage language can cause; however, it has to be considered within the broader context of discourse. In line with Foucault (1988) and other postmodern thinkers, it is this that shapes our views of reality along with our attitudes towards mental health, rather than terminology in isolation. For this reason by adopting other terms such as discrimination, the language as such is still what we are buying into. Freire (1972) argues that it is only through having sufficient understanding of a situation that the individual or collective can move toward change and liberation. Therefore, for me personally it is only by embracing the term and an extensive consideration of the concept that will enable a perspective transformation (Mezirow, 1981).

It is fair to contend that whilst there continues to be a negative association with mental illness and very public negative attitudes and perceptions, there will continue to be many that internalise this shame. As a conceptual issue, shame is intrinsically connected to self and involves the awareness of being judged by the other (Sartre 1993; Zahavi, 2014). Therefore, as supported by the literature review, education is a powerful and important vehicle to enable people to be open and discuss the issues: *"narrative approaches can help people*

with mental illness to develop a new life-story that is less focussed on their illness and deficits and more on resources and recovery" (Roe *et al*., 2010 in Rusch and Corrigan, 2013).

2.6 Self as the Site of Inquiry

My literature review identifies the gap which I am in a unique position to fill, to offer a piece of qualitative literature in the form of autoethnography on my lived experience of mental health stigma. Unlike some of the studies grounded in bio-medical understanding, an approach that is phenomenologically-orientated will arguably provide a 'felt' experience. It is anticipated autoethography will enable an exploration of my own deeply entrenched attitudes and perceptions to a side of self that had been buried for some considerable time. For this reason the doing of this autoethnography in itself serves as an anti-stigma process of self via the methodological processes, and the findings may then be used in practice.

2.7 Autoethnography for Transformation

Mindful of the above considerations it has been suggested there is a notably small but growing body of autoethnographic studies which focus on professional issues within Britain (Short, Turner and Grant, 2013) and the health and social care subject. Autoethnography would appear to be becoming more accepted as a credible methodology for this area (Chang, 2016). Exemplars include illness auoethnographies (Morella, 2008;

Richards, 2008), accounts of occupational therapy practice (Denshire, 2009), physical ill health (Sparkes, 1996), the experience of abortion (Ellis and Bochner, 1992), Social Work (Grise-Owens, 2011), mental health (Tillman-Healy, 1996; Short, Grant and Clarke, 2007; Muncey and Robinson, 2007; Short, 2009; Short and Grant, Burnard, 2007; Short 2010; Grant 2011; Liggins, Kearns and Adams, 2012; Axelsen, 2009; Jones, 2012; Grant, 2015b), Mental Health Nursing (Short, 2010; Struthers, 2012; Turner, 2012) and on mental health stigma related to living with obsessive compulsive disorder (Harrington, 2014). Harrington (2014) contributes to the literature that captures the subjective experience of mental health distress and stigma and calls for more research on this topic.

Belbase and Luitel (2008 p.86) have considered autoethnography as a way of linking lived experience to practice and research and the potential of such for "*transformative pedagogy*". Similarly, its use within educational research for enabling the lecturer to locate self and some of the many layers of identity within the historical and cultural context to deepen self-understanding, teacher identity and learning cultures (Austin and Hickey, 2007; Starr, 2010; Frambach, 2015). There has been (although this is changing) a paucity of university teachers researching their professional practice (Trahar, 2009). Therefore, I am positioned to conduct this 'living thesis' to address the research questions restated below:

- What stories do the researcher and 'others' have to tell about the experience of mental health stigma?

- How do these stories connect to the researcher's doctoral journey, professional identity and practice, within the wider, cultural, historical and ideological discourse?

2.8 Summary

The literature review has provided the impetus for this study and an important foundation from which to analytically reflect on my disorientating dilemma. Furthermore, it acts as a springboard to share my lived experience of stigma and its salience to my practice as a mental health professional, educator and researcher. The collective work supports the power of learning from lived experience to reducing stigmatising attitudes to mental illness. Therefore, the originality in this study is to share stories that may contribute pedagogically to new ways of thinking about stigma and moving beyond a stigmatised identity.

Chapter Three: Methodology and Methods

Moving now to a discussion of the scholarly framework, along with what will also become apparent is the 'product' of this inquiry: The aim, to offer you the reader a full explication for what I consider a compelling methodology. One, which I have grappled with and immersed myself in, as a novice researcher attempting to execute this research project. The first part of this section captures my philosophical journey. Here, I present an outline of my evolving researcher positionality, to the 'doing' of autoethnography. This includes a historical overview, with insights from the seminal thinkers at the heart of its genesis. In addition, the many different possibilities that were revealed to me as I developed my knowledge, confidence and the commitment to working with this method.

Secondly, I will examine some of the debates surrounding this approach, which includes analysis of both the ontological and epistemological framings of the method. Furthermore, justification for the use of autoethnography to explore personal 'stigma stories', applicable to mental health and identity. Finally, to provide justification for the capacity of autoethnography as a tool to implement within the health teaching and learning context, and the salience of its transformative potential for creative approaches to knowledge generation.

3.1 Philosophical Concerns

To begin, philosophical positionality provides an impetus to situate oneself in relation to reality, along with ones quest for 'truth'. From the start of my doctoral studies I began to consider in-depth my underpinning philosophical beliefs. It is fair to say, that whether you are undertaking quantitative, qualitative or mixed methods research, inherent within is the researcher's understanding of the nature of reality and the knowledge that permeates through the inquiry to address the specific research questions.

Therefore, careful consideration has to be given to the notion of a paradigm. Influential thinker Kuhn (2012) offered a depth analysis rendering this concept difficult to describe in concrete terms. Guba (1990) links it to belief systems that provide a framework to guide discipline specific research, or as Cresswell (2013 p.5) refers to a "*philosophical worldview*". It is within the definition of paradigms that the concept of 'epistemology' (which will be discussed later in this chapter) emerges. Depending on the particular paradigm that frames any inquiry, knowledge will be tested by different methods. Thus, paradigms are central to the methodological approach and the procedure for data collection and knowledge generation (Howell, 2013).

Scientific frameworks were built on deductive logic that postulates a general idea/s from which to develop theory, along with a 'testable' hypothesis (Bowling, 2009). The knowledge produced is viewed as

objective and complete (Popper, 2010). Whilst these understandings continue to remain influential and dominant, I struggled with the notion of objectivity when considering human consciousness. Clearly, one would have to question; would the objective exist without this? Howell (2013 p.3) states "*the idea of the objective has its embryonic existence in the subjective*". Therefore, this approach to the understanding of reality was one I struggled with.

Moreover, research is viewed through an appropriate theoretical lens. In relation to the advancement of theory, authors have attempted to examine relationships between theory, truth, knowledge and reality (Howell, 2013; O'Brien, 2006; Audi, 1999). Kumagai (2012 p.1141) highlights the value of considering theory from a 'hermeneutic perspective' which he broadly refers to "*as the study of interpretation and understanding*". Hermeneutics has its roots in textual meaning, initially, ancient Sanskrit and biblical texts, branching out further afield from the 19th century onwards guided by the works of Dilthey, Heidegger and Gadamer (Palmer, 1969 in Kumagai, 2012 p.1141).

Existentialist thinker Heidegger spent much of his life contemplating the meaning of terms such as 'being', 'truth' and 'becoming'. Heidegger aligns his consideration of hermeneutics to the Greek word for 'truth' (aletheia) which translates as 'enlightening' (1965, in Cooney, 2000 p.7). With this in mind, my thesis attempts to uncover meaning and reveal 'truths' around living with a stigmatised identity and the importance of this reality to my educational practice.

Therefore, the choice to undertake autoethnography is underpinned by how I view the world. Within the academic community what is regarded as good scholarly inquiry is judged relative to how all parts are linked together (Grix, 2004). Epistemology and ontology relate to reality, knowledge, truth and theory. Crotty (2003), asserts that ontology is concerned with trying to understand the essence of existence, situated amidst the complexities of reality.

The above deliberations confirmed what I intuitively knew, that I was a qualitatively situated researcher. My reality is shaped and understood through me, any representation is dependant of subjective and intersubjective experience. An interesting contention on the 'self' by George Herbert Mead (1934, in Hedges, 2010 p.2) is being "*is socially constructed in our everyday encounters with others and is reflexively involved in its experiences*". Self is further described by philosopher Smith (1994 p.xxvii) as "*bearer of a consciousness that will interact with whatever their world is taken to consist in*". Whilst contemplating the notion of 'truth' Kierkegaard believed an individual rather than a collective reality was the site for 'truth'. Conversely, the latter was a site of 'untruths' (1974, in Cooney, 2000 p.108).

Furthermore, I could not accept how knowledge and 'truth' are fixed and unchangeable. My world view of reality is that 'truths' are in a state of flux: dynamic forces that are highly open to change. A reality in constant interplay with culture, politics, economics and social factors within the wider sphere of the natural world is continually evolving, where no one

universal truth governs. On the contrary, there are multiple truths that change in line with epistemological historicity.

Thus, as suggested by Palmer (1993) there is 'space' to honour 'little stories' to strike a balance, one that prevents a "*sequestration of experience*" that may result from objective attempts to control the natural world (Giddens, 1991 p.149). Four Arrows (2008 p.18) states "*an epistemology of spirit encourages us all to be of service, to not get drawn into the ego nurtured in academia, and to keep diving into the wellspring of our own awe*". It is what he refers to as "*fully conscious subjectivity*" which he believes provides effectiveness in quite a different way to more traditional or objective forms of research. Therefore, subjectivity is central to interpretation of social meaning as opposed to measurement (Holden and Lynch, 2004).

3.2 Epistemological Positioning

The epistemological framing of this thesis is grounded in social constructionism, constructivism and critical pedagogy, the latter closely linked to critical theory that include the works of Marx, Weber, Emile Durkheim, Adorno, Horkheimer, Marcuse and Lowentah (Agger, 1991, in Sarroub and Quadros, 2015). The terms social constructionism and constructivism are often used interchangeably, but in fact they do have differences. The former is more concerned with the societal forces and structures that subconsciously shape our attitudes towards mental illness (Szasz, 1961; Foucault, 1988; Goffman, 1990a; Rusch, Angermeyer and

Corrigan, 2005; Rusch and Corrigan, 2013). Whilst the latter concerns our internal cognitive thought processes.

According to Gilbert (2008 p.514) social constructionism is "*a theory of knowledge that considers how social phenomena develop in particular social contexts".* So if we consider this relative to stigma one may assume this experience has developed within the social context, inherently influenced by cultural factors. Thus, within a sociological knowledge base stigma is a social construct that has emerged as a result of social processes and societal forces. The medical model, particularly the discourse that engulfs psychiatry, has shaped and moulded a world view, a particular way of thinking that has been influential in dictating the outcomes of the doctor/patient relationship and mental health care.

My teaching context is a favourable one for the implementation of a critical pedagogical research approach (Sarroub and Quadros, 2015). Denzin and Lincoln (1994) refer to social construction, as being 'socially enacted' or 'co-created' as too is this thesis. I would like to offer a "*human portrait*" of the lived experience of stigma and the "*interaction of agency and structure*" to move beyond (Jones, 2013 p.745). Relative to my discussion the project has important implications for what Lester (2012 p.276) refers to as "*workplace knowledge production*". A 'living thesis' that has evolved from its inception on the doctorate and the finished product is only a point in time from which the stigma education will continue, providing arguably greater 'authenticity' in my professional practice.

Goffman (1990a) was a very radical critique of the structures that contain 'difference' and the ways in which external stigma conveys an insidious societal presence. Moreover, he highlighted the processes that determine how the wider discourse becomes internalised within an individual psyche influencing the way someone thinks and feels about themselves. Of course, the latter is moving into a constructivist sphere, whereby cognitive processes are at play in creating someone's lived reality. A symbiosis of culture to mind and mind to culture (Bruner, 1990).

Furthermore, some have contended that any meaning of terms such as 'constructivist' and 'constructivism', may be shaped by the intentions of the researcher (Turner, 2012). These constructs are not fixed, instead having capacity and fluidity to unite. They are best regarded in line with Blumer as "*sensitising concepts*" (1954, in Schwandt, 1994 p.118). As Trahar (2009) asserts the nature of such research is iterative, with research and practice bound together but with the capacity to evolve. In addition, having the potential to "*bring new visibilities and awareness's*" (Denshire 2013p.7).

Hence, reality is constructed through both my internal and external worlds, thus the psychological and socio-cultural. Arguably, this is the point at which constructionism and constructivism unite (Mcilveen, 2008). Ontologically and epistemologically there is space through this union for emergent truths. The phenomenon of stigma has many similarities with this joining, through impact from the discourse and the subsequent psychic internalisation of this.

Critical pedagogy has its roots in constructivism and is a medium through which to explore subjective and collective attitudes and perceptions towards stigma within an adult learning context. From a social constructionist stance societal stigma forges individual and collective perceptions, which may then be cognitively challenged through education. This research is inherently critical and strives through a continual process of analytical reflexivity to move forward towards a place where mental health may be explored in a shared space without fear or shame (Hayes and Fulton, 2015). It is my intention to use critical pedagogy as a theoretical framework for giving consideration to and find meaning in the complexities of a 'lived stigma experience'.

As a mental health professional, educator and researcher with lived experience, I am positioning myself as both insider/outsider, or within and against my profession. This potentially has the power to create a tension that may weaken the divide between my professional work and personal life and open the divide between myself and others (Reed-Danahay, 1997; Denshire, 2013). Indeed, I walk the path, behind those who have gone before in my 'hybridity' (Grant, 2016b; Grant, Leigh-Phippard, Short, 2015; Grant, 2016c).

It was with much interest and trepidation I attempted to find a suitable methodology to explore stigma in mental health from a lived experiential perspective. This was further compounded by an intensification of my 'disorientating dilemma'. I wanted to capture the tensions I had encountered and how stigma had wielded a significant hold over my identity. To then offer

this 'truth' for the interpretation of my reader/audience for them to become cognizant of that knowledge, but also as Sartre (1993) would assert, 'truths' also resonate through 'feeling'. Within an interpretive inquiry the opportunity for sense-making is what gives it a possible transformative potential. In this case, to create empathic learning spaces for feelings to be allowed in. Arguably, emotions are rather like stigma; social-phenomena, influential in forming a particular orientation.

Mindful of the above, I was compelled to do 'authoethnography'. Auto (self), Ethno (socio-cultural connection), Graphy (Application of research process) (Reed-Danahay, 1997). The strength of this method is that it allows one to draw on one's own personal lived experience (Ellis, 2004). Proponents of this relatively new design claim it has multi-dimensional qualities (Ellingson, 2009). Its roots are deeply entwined within other narrative forms of inquiry such as ethnography. Narrative research allows for a more holistic path to the understanding of stigma (Harrington, 2014). However, the significant and defining difference within this method is that I will be closely examining 'self' as the site of inquiry rather than observing participants.

Autoethnography had its genesis in what academics have alluded to as the 'crisis in representation', "*a quiet methodological revolution has been occurring in the social sciences; a blurring of disciplinary boundaries has occurred*" (Denzin and Lincoln, 2005, p. ix). Seminal pioneers in this field have acclaimed that the method is one with potential to bridge the boundaries in social science. (Reed-Danahay, 1997; Ellis 2004; Ellis and

Bochner, 2000). Wall (2006) states that within a postmodern paradigm there is space for the emergence of more critical theories. An example of such is feminist theory as a means to providing a counter narrative to dominant discourses that have their roots in masculine ideology and power. The latter conferring a potency that is oppressive and "*reduces us as human beings*" (Brown, Crawford and Hicks, 2003 p.236).

Additionally, the writing style will be presented as a narrative that features emotionally situated, lived experience, giving prominence to other 'voices' and interpretation (Ellis, 2004). It does not espouse any objective truth rather a lived experience of my own construction of reality (Dyson, 2007; Turner, 2013). Ellis, Bochner and Adams (2011) see the doing of autoethnography as having dual qualities, in being both the 'process and product'. Similarly, Chang (2008) refers to this approach as both 'method and text'.

Autoethnography has been defined as an:

"Autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural. Back and forth autoethnographers gaze, first though an ethnographic wide-angle lens, focussing outward on social and cultural aspects of the personal experience; then they look inward, exposing a vulnerable self that is moved by and may move through, refract and resist cultural interpretations" (Ellis and Bochner, 2000 p.739)

Or

"….a qualitative research method that enables researchers to use their autobiographical and contextual data to gain a hermeneutical understanding of the societal context and in turn, a socio-cultural meaning of self" (Chang, 2011 p.13).

As stated by others who have traversed this territory, the decision to do an autoethnography was daunting. I spent a year reading other academic accounts in order to learn from such examples (Wall, 2006; Denshire, 2013p.4). These included, evocative (Ellis and Bochner, 1992; Ellis, 1999; Ellis, 2004; Tillman-Healy, 1996; Muncey, 2010; Short, Grant and Clarker, 2007; Grant, 2011; Turner, 2012; Short, Turner and Grant, 2013), interpretive (Denzin, 2014), performative (Spry, 2001; 2016) and last but not least analytical (Anderson, 2006; Struthers, 2012). I was intrigued and inspired by some of the pioneers in the field (Hayano, 1979; Ellis, 1999; 2004, 2007, Ellis and Bochner, 2000; 2006, Anderson, 2006; Chang, 2008; Richardson, 1994; Tillman-Healy, 1996; Muncey, 2005; 2010; Reed-Danahay, 1997; Short, Turner and Grant, 2013).

Additionally, the small body of studies in the health subject made it apparent to me that an autoethnographical inquiry on stigma was possible. Such would provide opportunity to give close attention to some of the interconnected complexities of a phenomenon, where power issues are central, in order to convey an embodied interpretation of a stigma experience from which to challenge negative attitudes. Within my role as

an academic, I am mindful of power dynamics and how these operate on many levels within the context of my teaching and learning. I strive to uphold a sensitivity to such, in order to foster a more open dialogue with learners. However, this can be difficult when students may have pre-conceived ideas on the lecturer's status, delineated by their perceived specialist knowledge.

Furthermore, one of the factors that attracted me to autoethnography was the possibility for flexibility with the method and approaches I could adopt. Critics would deem this as ensuring the genre lacks academic rigour (Delamont, 2007). However, it has been suggested, and I would be inclined to agree, that this adaptability conjures conditions that are best aligned to my chosen topic and any insights that may arise (Chang, 2008). The very nature of an evolving inquiry may mean that there are changes throughout (Chang, 2008).

My initial interest was with an 'analytical' approach, due to the seeming consensus that this serves to improve validity techniques normally associated with enhancing trustworthiness (Anderson, 2006; Atkinson, 2006; Chang, 2008; 2011; 2016; Vryan, 2006; Struthers, 2012). This gave potential to add another layer of data from 'others' in order to allow for triangulation of the data and greater rigour (Anderson, 2006). That said, triangulation tends to align a more to positivistic stance and for this reason may be considered somewhat restrictive for autoethnography which is situated within a postmodern paradigm. I will revisit this contention a little further on.

Many have debated the different genres and deemed that with the analytical approach the personal account is not as dominant as the underpinning *"empirical-theoretical story"* (Burnier, 2006 p.415). Conversely, an evocative approach offers space for an expressive narrative which if accompanied with a high degree of analytical reflexivity may well enable a forward direction towards highlighting the sociological concept of stigma (Ellis, 2004). At the outset the analytical style appeared more aligned to the qualitative format that I was more familiar with.

However, Ellis and Bochner (2006) argue Anderson's stance reveals a distinct divide between analytical and evocative autoethnography. Some contending the latter serves to inhibit a more creative style (Muncey, 2010). Interestingly, when considering this in relation to Freire's (1972) notion of 'generative themes', the two would appear to be diametrically opposed, and arguably such movement a pre-requisite for assimilation. Therefore, this study in line with Jones (2013) has attempted to weave elements of both with the intention that the evocative nature of the stories bestows a capacity to resonate with the reader. This then combined with a further process of interpretation to reveal insights, recurring themes and meaning from the stories.

Similarly, this decision was also driven by concerns voiced within the literature for the researcher to align to a particular approach. It is suggested that this apparent need to define and create neatly delineated types is reminiscent of the "*gendered dichotomies*"- that have been created

within social science discourse "*Personal, emotional, literary-poetic, and descriptive knowledge historically has been constructed as feminine, whereas scholarly, rational, analytical, and theoretical knowledge has been constructed as masculine"*. And the gendered associations is being mirrored in autoethnography (Burnier, 2006 p.416).

The above debate triggered a shift in my thinking and I became more intrigued by the evocative style (Ellis, 1999; 2004; Muncey, 2010; Tillman-Healy, 1996; Ronai, 1995; Short, (2010); Turner, 2012; Rath, 2012; Short, Turner and Grant, 2013). Ellis (2004) contends that in order to 'feel' and understand particular issues becoming emotionally intelligent is important. When this is considered in relation to stigma arguably it as an internal entity it has been 'silenced'. Certainly the case in my own experience, and any connection with feelings related to this had become difficult. Therefore, in view of this the doing of autoethnography could potentially be 'freeing'.

Mindful of the above and in line with Trahar (2009 p.3) I intuitively felt a powerful connection with this methodology as I was seeking to unravel the meaning of my stigma experiences in synergy with a set of research processes which "*itself was a series of experiences*". For this reason, I intend to provide the framework for a layered account (Ronai,1995) that weaves within a high degree of analytical reflexivity as the thread that connects and interconnects self, 'others', culture and history to produce a narrative of the lived experience of stigma in mental health and its connection to my practice. As I was striving for a fusion of the analytical

and evocative the story and analysis are separate. The stories may well invoke evocative responses from the audience. Through them the possibility to conjure such a reaction, a verisimilitude or an "*invitational lacunae*" from within the many layers (Rath, 2012 p.1). It is hoped that using a combination of both analytical and evocative techniques will serve to strengthen the trustworthiness of this study.

Autoethnography and indeed this inquiry aligns itself with what some would describe as emancipatory dialogue with the potential to connect and provide space to give voice to those previously silenced (Denzin, 2005). Having had preliminary grounding in both cultural history and medical anthropology, the theoretical underpinnings of these bodies of knowledge also seemed to have strong parallels to a study that is going to consider the social phenomenon of stigma in mental health from a deeply personal perspective. In addition to this, how historicity or grand narratives have influenced the discourses on this topic. This autoethnography has arisen from my disorientating dilemma, and the doing of such will enable me to step out of a suffocating liminal space to become what Jones (2013) refers to as a 'border crosser'.

Essentially, I intend to share a story about a story, my story in an attempt to contribute an alternative to the more scientifically grounded inquiries of stigma previously discussed in Chapter Two. The stories will be considered within a reflective account that captures "*ones own history to relive it*" (Mezirow, 1978p.100). To convey a sense of transition, moving through stigma in an emancipatory way in order to be more authentic in my educational

practice. Denshire (2013 p.1) refers to autoethnography as a 'transgressive account' that when situated within professional practice, allows space to explore and readdress power dynamics. "*Autoethnographers often blur boundaries, crafting fictions and other ways of being true in the interests of rewriting selves in the social world*." Through such processes there is capacity for removing barriers that may present as a block to my work as a professional and within other avenues of my life (Reed-Danahay, 1997).

The intention is to merge my personal narrative or as Rath (2012 p.1) would state my "*narrative inheritance*", woven within and alongside the narratives of 'relational others', to culturally situate the 'lived experiential stories' of mental health stigma. Frank (2010) refers to stories as 'socio-narratology'. This approach to narrative analysis is centred on 'interpretation' of stories and therefore more akin to 'meta-interpretive' or 'dialogical interpretation'. It is anticipated the weaving of personal stories will add further layers of subjectivity, making for rich detail (Adams, Holman-Jones and Ellis, 2015).

Furthermore, within the undertaking of a Professional Doctorate, a central imperative is to link knowledge to practice. In this case teaching in health and well-being, in order to create space for 'anti-stigma' pedagogy. I am uniquely positioned as both expert and service user to undertake this and utilise the knowledge gained from this study in my pedagogical practice. The doing of autoethnography provides opportunity for "*catalytic and educative authenticity*" (Hayes and Fulton, 2015 p.12). The centrality of learning from experience in line with the methodology to connect self to the wider whole

(Weil and McGill, 1989; Hull, Redfern and Shuttleworth, 2005). Due to the personal nature, as has been expressed by others, I found it difficult trying to decide what and what not to share with the audience, and as a novice researcher felt a degree of pressure to achieve a comfortable position (Hall, 2012; Turner 2012).

3.3 Reflexivity

Reflexivity involves 'self' and the turning back of thoughts; it suggests a mindful process of contemplating experience from within a situation (Bolton, 2010; Johns, 2009). Within social science research this activity is held as an ideal (Hedges, 2010). The concept and practice of reflexivity as many contend is essential for carrying out good qualitative studies (Newton *et al.*, 2011; Finlay, 2002; Cousin, 2013; Hosking and Plutt, 2010). Taggart *et al.* (2013 p.64) further suggest reflexivity is important for considering how our beliefs shape research or in Glaser's (2013) view, the importance of "staying open" particularly within the analysis stage to increase the power of description. Perhaps in line with more contemporary thinkers on this subject one recommendation may be further consideration on ways to bring oneself explicitly and mindfully into the research process (Cousin, 2013). A further consideration as Evans (2013) argues, is to have an awareness of bias throughout the process, which can only be acquired through reflexivity. Arguably, it is this subjective bias that is one of this study's strengths.

Reflexivity may be viewed as a social constructionist/constructivist concept that ultimately any "*understanding of reality is a product of our negotiated constructions of it*" (Cousin, 2013 p.3). Smith (1990) posits the only way to understand a socially constructed reality is to know it from within. So here I, along with the influence of underpinning knowledge enter into a dyadic process to develop new meanings. Autoethnography, is a highly reflexive methodology where the text and author are deeply intertwined. Arguably, the credibility is strengthened by the author's attention to rigorous and ongoing analytical reflexivity and reflectivity that permeates all aspects of this text and method. Alvesson and Skoldberg (2009 p.244) state *"the research process should be explicitly guided by individual researchers' willingness to reflect upon and listen to their own feelings*". Which is a central part of the process of this method.

Social theorist Bourdieu, may be credited for making a substantive offering to thinking around the concept of reflexivity. At all times during his scholarly career, he regularly cast the lens over himself. However, his writing style did not always reflect or make apparent that this was the case (Bourdieu and Wacquant, 1992). A particular area that would appear to have garnered his intrigue was the way in which professional language had a capacity to wield power.

Of course, Bourdieu's thinking around the concept of reflexivity was at variance to others, as he saw a collective capability to act as a dynamic to foster social change. He viewed this combined force to be more significant than if an individual were to engage in such. A process that had the

utilitarian effect of supporting sociological knowledge, as opposed to attacking these structures. It would appear to me there are parallels with critical pedagogy, and Freire's (1972) notion of generative themes. Thus, the thesis is providing insights for educative dialogue to allow my students to engage in discursive and reflective practices to consider the negativity linked to mental health.

Finally, for me personally, there is a compelling potency within this method, the journey is not a linear one, instead involving adjustments along the way. Denzin and Lincoln (1994 p.479) posit "*The processes of analysis, evaluation and interpretation are neither terminal nor mechanical. They are always emergent, unpredictable and unfinished*". For this purpose a high degree of reflexivity has been maintained throughout to ensure I remained cognizant of the links between epistemology, theory and methods and the need to continually review issues as the project progressed (Chang, 2008). This awareness is central to remaining receptive to the possible complexities of synthesis, and the unfolding nature of such inquiry (Punch 2014). I will now move to consider the methods that serve to enhance the axiology and trustworthiness of this study, with detail of the data collection and analysis that enabled the writing of my story.

3.4 Methods

3.4.1 Ethics

Ethical considerations are paramount to all research endeavours and deeply entwined with our humanity (Turner, 2013). One particular area, unique to this method is 'relational ethics', which require the ongoing attention of the researcher at every stage of the process, to continually question and reflect, search and challenge intentions (Ellis, 2007). What I have discovered on this journey, is the complexities and particular considerations that may arise when undertaking autoethnography.

Moreover, there appeared a lack of consistent guidance pertaining to this approach. For this purpose, my proposed study has been directed by Tolichs (2010) Ten Foundational Guidelines (Appendix 3); Tullis (2013); Ellis (2004); Turner, 2013; Adams, Holman-Jones and Ellis (2015). Jarzabkowski (2012 p.10) asserts that it is important to give attention to ethical issues, that may unexpectedly present in the course of the research and this may serve to influence the study to such a degree "*that emotional labour is performed*". The doing and dissemination of this research along with engagement with my siblings involved an awareness of both my and their emotions.

In addition to the use of memory as data, I conducted dyadic interviews (Ellis, 2004) involving two siblings within a "*relational constructionist perspective*" (Hoelson and Burton, 2012 p.92). Upon receipt of ethical approval I was guided in my actions by the protocol set out by the

University of Wolverhampton Institute of Health Ethics Committee within the Faculty of Education, Health and Wellbeing (Appendix 4). My siblings were given information sheets highlighting the purpose of the study, along with consent forms. They had time to consider and decide whether to participate and gain more information if required. In addition to this, guidance was proffered on the 'interview' process and the importance of confidentiality (Appendix 5 and 6). Written consent was sought from them prior to commencement (Appendix 7). They understood that participation was voluntary with the right to withdraw at any point. I was mindful of allowing time at the end to debrief if needed. The interviews were recorded, transcribed and stored in a secure facility, and on a password protected computer.

3.4.2 Relational Ethics

Levinas advanced ethical thinking to include consideration of personal responsibility towards others in relation to '*alterity*' or the capacity to do good in the face of the other (Levinas, 1987). The very nature of writing about the self always means others are implicated (Ellis, 2007; Chang, 2008; Roth, 2009; Turner, 2013). Therefore, confidentiality is important in relation to autoethnography and was maintained by ensuring that it was not possible to identify individuals or specific contexts from the data. However, this is more problematic when referring to siblings (Ellis, 2004; 2007; Tullis, 2013; Turner, 2013; Adams, Holman-Jones and Ellis, 2015).

Hence, I am accountable for what I disclose about myself and siblings. With this in mind it is important to maintain recognition of my "*narrative privilege*" (Adams, 2008) and in view of the above my "*narrative conscience*" (Poulos, 2008 p.46). As Porter- Abbot (2008, p.40) contends "*narrative is an instrument of power*" and as the researcher I paid ongoing attention to these concerns. To mitigate against these issues, I shared the stories with my siblings, creating opportunity for the practice of 'process consent' to ensure voluntary participation throughout (Denshire, 2013; Adams, Holman-Jones and Ellis, 2015). The practice of member checking served to focus on inaccuracies, but also an opportunity for reflection on the differences that the process may yield (Biscomb, 2012). Arguably, interviewing my siblings could prevent me from being objective and viewing the transcripts as a "*detached outsider*" (Biscomb, 2012 p.256). Importantly, not all the stories involved my siblings and as the research progressed, self became the prominent site of inquiry.

Mindful of the above, it was necessary to uphold the principle of not publishing anything I would not have been happy to show others inferred to within. However, I have shared stories relating to the memory of a brother who is now deceased. Of course, decisions on what to tell of those deceased is arguably more difficult from an ethical perspective. The processes described above ensured discussion on what to tell and how to tell it. I have taken care to only share from the interviews what my siblings were happy with, being mindful at all times to uphold the principles of beneficence and non-maleficence.

Relational ethics involves doing what is important to be 'true' to self, but without compromising others. But as Turner (2013 p.220) highlights this is at variance in a socially "*constructed ontology*", where what I think may be different to another's. For this purpose, it is important to note that this inquiry is my construction or interpretation of events, layered and informed by others, whose voices added further texture to my story.

3.4.3 The Ethics of Self

Finally, as 'self' is the primary site of inquiry, ethical considerations are also highly important in relation to myself, particularly when working with memory and referring to self and others as part of the process. Consideration has been given to my own vulnerability throughout this process. Attention to self-care was supported through mechanisms such as supervisory meetings, debriefs, and ongoing attention to reflexivity through the maintenance of a research journal. (Muncey, 2010; Adams, Holman-Jones and Ellis, 2015; Tullis, 2013). As Adams, Holman- Jones and Ellis (2015 p.65) assert "*you become the stories you write*" and in accordance with Tolich (2010) should be viewed as an 'inked tattoo'. I contemplated doing this story through the medium of a composite character (Ellis, 2004). However, this felt uncomfortable in the face of stigma; a concept that needs to be talked about. For too long, mental ill-health has been silenced and many people have lived with the consequences of this quiet. Therefore, the decision was taken to present self as self and wear my 'inking' with full pride. Thought provokingly Turner (2013) argues the ethical strength in autoethnography is that it

does not seek to assert an absolute objective truth, rather like art, it seeks to resonate with the audience for them to make their own meaning.

3.4.4 Data Sources

As I am both the subject of the study and researcher (Chang, 2008), the data sources in addition to the interviews drew on a combination of personal and professional artefacts (detailed below) over approximately 12 months from gaining ethical approval (journal work had commenced the year before). A timeline of this process is captured in table 3.1.

Sandelowski (2011) asserts when undertaking this method of inquiry, one has the freedom to draw on a variety of data collection strategies. Having this license and creativity may serve to raise authenticity and provide greater 'crystallization' of such data (Richardson, 1994; Ellingson, 2009). The data gathering process was varied and initially did not place one method over another. It began with journal writing and audio recordings to capture my thoughts and feelings on not only the anticipated data, but also around my working with an evocative and analytical autoethnography. However, a central source of data became the use of memory to gather stories and field notes.

Further to this it included both textual artefacts and non-textual material. The former through writings, historical documents, and interviews the latter photographs, and audios. Additionally, Muncey's (2005; 2010) refers to a *snaphot* which she describes as "*a moment frozen*

in time" (2005 p.71) and this was useful with memory work through the medium of family pictures, artefacts and symbolic representations. Time was spent looking, thinking and remembering when working with this data and recording my feelings and memories. This concept was useful when thinking about how to later present the stories. Ellis (2004 p.68) *asserts "…one of the values of this approach is its flexibility, you must be aware of the possible dynamics and open to improvisation and changing strategies along the way to better match constraints and needs of the project".* The iterative nature of the inquiry at times necessitated the need for further collection of data to strengthen the focus, with structured steps to interpretation along the way (Chang, 2008). The authenticity and integrity of research may be subject to greater scrutiny when involving an insider perspective and the layering of deeply personal accounts that rely on the use of memory (Chang, 2008). Chang (2008 p.71) refers to memory as the 'building block' of autoethnography.

As Frank (2013) asserts, memory is in a continual cycle of forming and reforming. Previous research done on the "*truth in memory*", aligns with my philosophical stance; memory is a 'reconstruction' of events of the past in the present (Lynn and McConkey, 1998). Sartre (1993, p.108) would argue that the past is gone, "*melted away into nothingness*". How does this then impact on memory which has been drawn on to analyse the lived reality of stigma? If it has gone, how can it be captured, recorded and hold any authenticity? Our memory according to Sartre (1993) is a '*modification of our being*', in the present moment. This then begs the

question of validity, however, it is interpretative and open to interpretation.

To further assist with memory work I conducted a series of self-reflective activities guided by Chang (2008). Following her suggestion this included an autobiographical timeline to help with the chronological ordering of events. This allowed me to focus on specific junctures to capture important data on stigma and its connection to my practice. Following this I performed a series of writing exercises and visualization techniques. For example, the process of 'free-writing' (Holly, 1989) to capture the swirls of memory that would surface often at the most unexpected moments, along with 'free drawing', which is thought to be a powerful tool to evoke memory (Chang, 2008), and utilise as a reflective tool.

The reflexive dyadic interviews with 2 relational others were conducted December and January 2016-17. Reflexive dyadic interviewing is a dynamic technique pioneered by the leading proponent in the field of autoethnographical inquiry Caroline Ellis. The intention is to engage with the participant in a more conversational style of encounter that places central importance on the interviewee's stories, whilst simultaneously considering the reflections of the interviewer and how this synergy may produce deeper meaning. This reflective method aims to add nuance and layers to the participant's story (Ellis, 2004p. 62). A final note here is the dyadic with siblings enabled a greater "*embodied relational understanding*" (Todres, 2008 p.1566).

The unstructured approach employed facilitated flexibility with the process (Ellis, 2004). Whilst interviews are not usually the first choice for autoethnography where self is being researched, it does present opportunity to stimulate memory and gain awareness of any gaps, get previously unknown information, as well as my siblings perspectives on the topic (Chang, 2008). In keeping with the analytical elements, it also constitutes that necessary dialogue with other informants beyond self (Anderson, 2006).

The gathering of the data has been accompanied by the technique of systematic self-observation (SSO) and reflection or "*systematic sociological introspection*" (Ellis, 1999 p.671) on both the textual and non-textual artefacts. Throughout the data collection process I also engaged with continuous self-observation through a reflexive journal and audio recordings in order to gather accurate field notes of lived experience "*….social life is a complex, situated, occasioned, fast-paced, and improvised stream of phenomena that unfolds from moment to moment*" (Rodriguez and Ryave, 2002 p.5). The above processes allowed for a dyadic conversation with self throughout. This dynamic quality ensured the inquiry was "*resonant with possibilities*", that a dialogue with self may enable (Giddens, 1991 p.77).

Rodriguez and Ryave (2002) suggest SSO stemmed from the ideas of Erving Goffman and view this method as important to engage the personal experience, in this case the social phenomena of stigma. As indicated earlier in this chapter SSO has involved the implementation of

a high degree of reflexivity, which Giddens (1991) asserts is an important element for what he refers to as the 'reflexive monitoring of modernity'. As highlighted by pioneers in this field, the integration of experience of self and others has the ability to generate a sense of reality in order to convey the complexities of stigma relative to the cultural context (Adams, Holman- Jones and Ellis, 2015).

Due to the iterative nature of this inquiry data collection has been an ongoing process, involving the simultaneous analysis of the data, moving back and forth in a continual 'flip-flop' (Strauss and Corbin, 1998) to make sense of that collected and if necessary gather more when the need arose. Of course, data saturation is therefore difficult to establish with this method of research (Muncey 2005; 2010; Chang, 2008; Turner, 2012). I took the decision when to stop, as well as setting boundaries as to what to include and omit in the final set of stories. The choice driven by the most salient themes to emerge from data interpretation, and the most powerful and pertinent to create evocative and analytical stigma stories.

TABLE 3.1 Sample from DATA COLLECTION LOG: Adapted from Chang (2008 p.120)

Data Collection Strategy (primary labelling]					**Data Content (secondary labelling)**			
Date Set # Place	***Date*** *When*	***Collector*** *Who*	***Type*** *What*	***Location*** *Where*	***Time***	***People Involved***	***Source***	
1	2014-2017	Self	**S/O**-journal	U-home	Duration of Thesis Module	Self	Self	Home/work
2	9.12.15-12.12.16	Self	**S/R** Audios	U-home/work	Duration of Thesis Module	Self	Self	Home/car
2	July 2016	Self	**Vi**-photos	U-home	1972-2017	Self/family	Self/family	U
4	July 2016	Self	S/R-culture-gram	U-home	2016	Self/family	Self	U
5	July 2016	Self	S/R drawing	U-home	1972	Self/Institution	Self	U-O
6	August 2016	Self	**Do**-HMR	U-home	1982-2016	Self/professionals	Artefact Copy	U
7	21.12.16	Self	Interview	U-home	1965-1986	Self/relative	Sibling 1	U
8	02.01.17	Self	Interview	U-home	1968-1986	Self/relative	Sibling 2	U

Notes: **S/R**=self-reflective, **Vi**=visual, **Do**=document, **S/O**=self-observational, U=UK, O=Other

3.4.5 Data Analysis

As indicated in Table 3.1 and discussed above, I have drawn on many different forms of data which has necessitated a need for careful management in order to then conduct analysis. As with other forms of narrative inquiry the analysis of data may not be a straightforward process. These methodologically emergent qualities have meant that I have remained open and attentive at all times to these possibilities (Chang, 2008). The main issues I struggled with was the voluminous range collected and the realisation that early organisation of such would have been sensible.

A 'data log' was used (Table 3.1), to document items of data collected for the research and this also indicates the timeline of this process. Individual items are known as a 'data set'. The purpose of such is to clearly define each data set by a process referred to as primary and secondary labelling (Chang, 2008). This serves to assist both data generation and management, along with contextualization conferring a transparency in my audit trail. The range of data documented through primary labelling reveals a range of contributors and sources pertinent to self and practice. Finally, this organisation afforded opportunity to review possible deficits and necessitate further collection of data.

The positioning of self at the heart of the inquiry means that I have lone responsibility for the collection and interpretation of the data (Chang, 2008). Although data gathered from my siblings was subject to process consent. The

implementation of a study that has both analytical and evocative qualities has required considered contemplation. Those situated in the analytical school suggest a thematic approach, some recommending constructivist grounded theory for analysis (Anderson, 2006; Atkinson, 1997; Chang, 2008). However, others would suggest this conflicts with the nature of a creative approach to interpretive inquiry with possibilities to resonate with the audience (Ellis, 2004; Muncey, 2005; 2010). Would an attempt to provide analysis move away from its transformative potential? Ellis (2004) suggests that if adopting a more analytical stance, then she prefers to use the term 'narrative analysis of themes' which has many similarities with the coding methods of grounded theory but is not as rigid and prescriptive. An example of a thematic analysis of narrative, is provided by Karp (1997) 'Speaking of Sadness', who organizes stories into themes around the stages of the illness depression using examples of story to emphasis the theme.

When considering the differing approaches, it is also possible according to Ellis (2004) to use a combination of the above strategies. For example, she states you may wish to position yourself by the telling of your story, then move to the analysis of other stories which can then be connected back to your story. The choice may be influenced by factors such as subject, intended audience and style with which you are most comfortable with in order to develop my voice (Ellis, 1999).

I conducted an analysis of my data to arrive at the themes that then became the stories. The data analysis and interpretation was time

consuming, particularly as autoethnography focusses on making meaningful connections to the wider cultural context. The assimilation of such wide and varied forms of data sets proved challenging. There were many sub-themes (Appendix 9) within the data and for this purpose to assist in this lengthy process Chang's (2008) 10 stage framework for data analysis was utilized, providing the scaffolding which afforded greater transparency to the process and emerging themes (Table 3.2). Chang (2008 p.128) asserts that these sets should not be viewed as separate entities rather a 'balancing act' between fracturing and connecting, between 'zooming in' on the detail of my experience and 'zooming out' to the broad socio-cultural and political context and the significance of these to self.

Many would refer to analysis and interpretation as one however, Chang (2008) provides a detailed explanation of how they differ. The former being opportunity to decipher the data and the meanings that emerge from this. The latter is opportunity to adopt a bird's eye view of this analysis and make linkage to the wider cultural significance. When reading Chang (2008) it is clear that she does not set a descriptive template by which to analyse and interpret the data, and as such I have been flexible in its application.

This analysis involved a review of all the data sets, looking for recurring cultural themes and patterns, identifying exceptional occurrences, analysis of things included and omitted, temporal connections, relationships with self and others, comparing self with others,

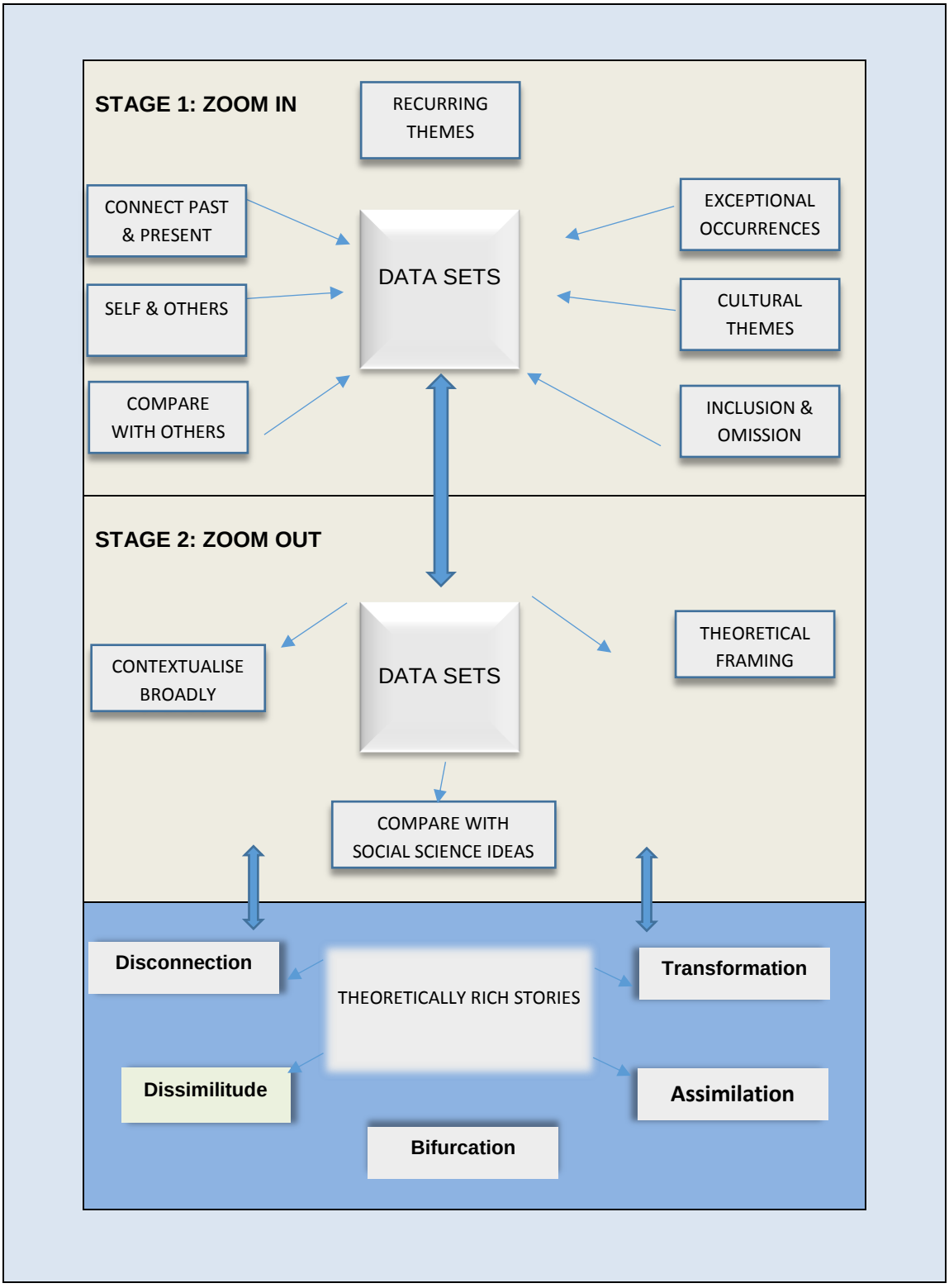
contextualising broadly and connecting with sociological concepts and theory (Chang 2008). Interview transcripts and all data was initially read, then re-read in order to gain an overall impression in relation to my study aims. The themes emerged from a systematic, detailed and thorough manual search of all the data sets, followed by colour coding areas of resonance and to highlight recurrent themes, with my specific research questions in mind (Appendix 8).

As this process was ongoing I was already becoming aware of the emergent themes, however the framework enabled a better organisation and interpretation of the insights that were starting to reveal themselves (Appendix 9). Data analysis begins at the point of data collection and this analysis may require the collection of further data. Thus, a process that allowed the research to be refined and more pertinent data collected when necessary and the application of interpretive processes on an ongoing basis (Chang, 2008) and reflects the notion of crystallisation (Richardson, 1994; Ellingson, 2009). The analytical process was deemed important to make sense of deeply personal and existential issues. The final set of themes were the most salient (with ongoing consideration to relational ethics) in which to present the stories and connect to theory (Appendix 10).

What I have found inspiring about this approach is the opportunity it afforded me for creativity. Richardson (1994) refers to this as Creative Analytical Practices (CAP). Ellis and Bochner (2000) state it allows considerable freedom with its imaginative presentation. Indeed, what

would seem its nebulous and flexible approach to analysis has been the exciting part of the process. My stories will be evocative but also have analytical dimensions embedded throughout. As Ellis (2004 p.194) states "*…there is nothing more theoretical and analytical than a good story*".

Table 3.2: Data Analysis Model (Adapted from Chang 2008)



Embedded within my 'disorientating dilemma', as part of the bigger story was deciding how to "*lean in*" to autoethnography (Snyder, 2015 p.93). Indeed, the learning of different approaches open to me was a generative process in itself. Coming from a postmodern position, where truths are multiple and dynamic, I did not want the analytical process to stifle this. However, to maintain a balance with the requirements of the professional doctorate I found Chang (2008) provided a 'comfortable' framework for managing the reflective processes, analysis and interpretation. In line with others it enabled me to find a starting point (Snyder, 2015) to this method. For this purpose, it was used for utilitarian function and offered structure to what was a flexible, iterative and holistic overview of my data, one that enhanced the analytical reflexivity to arrive at the themed stories. Some of the stories were partially written as memory data, whilst others evolved from the analytical framework.

Moreover, from an axiological point it allowed me to consider how I would share my stories and reveal a long hidden identity. A journey that was not only liberating, but also painful and for this reason attention to self-care was a constant consideration. The final stories were the most salient to address my research questions, but also ones that had most resonance for me. Ones, I could extend in practice with the possibility for new meanings to be found (Denzin, 2014).

Five broad themes emerged, which are conveyed in the stories presented in Chapter Four. The themed stories were subjected to further exploration within the ideological, cultural and historical contexts that frame the

discourse, using a structure previously offered by Tsang (2000) and Biscomb (2012). For this purpose, the intention is to tell the story/ies and then provide 'sense-making' connecting to theory, to create what Ellis (2004) would refer to as a 'theoretically rich' story. Stories were deemed a more evocative way of conveying my experience of one of our cultures most taboo subjects. Furthermore, as is metaphorically reflected within the title conveying a sense of journey as a medium Muncey (2005) to address my research questions.

The themes elucidated were *dissimilitude, disconnection, bifurcation, assimilation* and *transformation*. The emergence of these dependent on my interpretation, giving prominence to myself as researcher situated within the methodological process. Interestingly, they may arguably reflect the nature of my own attitudes after self-exploration of stigma through this autoethnographical inquiry. Careful consideration was given to the way in which the stories have been narrated in order to preserve credibility (Muncey, 2005), along with their trustworthiness (Guba and Lincoln, 1989).

3.4.6 Trustworthiness

Garratt and Hodkinson (1998), discuss some of the mechanisms for assessing an inquiry of self, in relation to the 'traditional criteria' that is utilised for evaluating qualitative research. The above authors, along with others have questioned the suitability of such when judging autoethnography. To enhance the trustworthiness of this thesis I follow in

the footsteps of those who have gone before me and draw on Guba and Lincolns (1989) criteria for authenticity (Starr 2010; Struthers, 2012). In particular "*ontological authenticity*", and the importance of advancing my emic perspective to transform the way I conduct myself within my stigma pedagogical role. Similarly, "*educative authenticity*", involves gaining a better understanding of self, through self-reflexivity and dialogue along with an examination of the experience of others involved in the process.

The criteria of "*catalytic authenticity*" centres on the actions that arise from the evaluation processes within the inquiry, as well as the research processes. Within the discussion chapter I have provided theoretical discussion on the transformative and generative nature of the journey and the implications this has had on both a personal and professional level and how these may influence practice.

Richardson (1994) and Ellis and Bochner (2000) have attempted to provide determinants that may need to be examined when adopting research based on storied accounts. It has been suggested that consideration is required on the qualities that go to make a 'good story' in balance with what may be deemed acceptable as good trustworthy scholarship (Holt, 2003). As this inquiry embraces both an evocative and analytical style, the table (Table 3.3) below present's criteria important for each. Further to this the issue transferability, a concern in all research, is not applicable in the same way with autoethnography. Ellis, (2004 p.195) asserts, that it is difficult to generalise from story and for this reason a *"story's generalisability is always being tested"* by the

readers as they determine if it resonates with them and their own lived experience.

Moreover, issues of validity relative to this genre have been considered ill-fitting. As indicated earlier and now detailed Richardson (1994) uses the metaphor of a crystal or the concept of crystallisation as a more postmodern way of thinking about validity (Ellingson, 2009). Richardson states crystals have a multi-dimensional quality which impacts on the way they refract the light. Dependent on their position the light reflects in many ways and influences how it is then appreciated. Therefore, instead of thinking in terms of triangulation, the process of crystallization is more in keeping with a postmodern world where there are a variety of genres, styles and possibilities for interpretation.

Caroline Ellis talking from her own experience as a seasoned autoethnographer states "*I start from the position that language is not transparent, and there's no single standard of truth. To me, validity means that our work seeks verisimilitude; it evokes in readers a feeling that the experience described is lifelike, believable and possible"* (Ellis 1999, p.674). Hence, when considering verisimilitude, what the author is striving toward is conveying a resonant quality through the story, such that the reader may relate to their own experience and reality. (Ellis, 1999). Thus, the pedagogical stories creating opportunity to raise awareness of issues which may be of use when working in the mental health field.

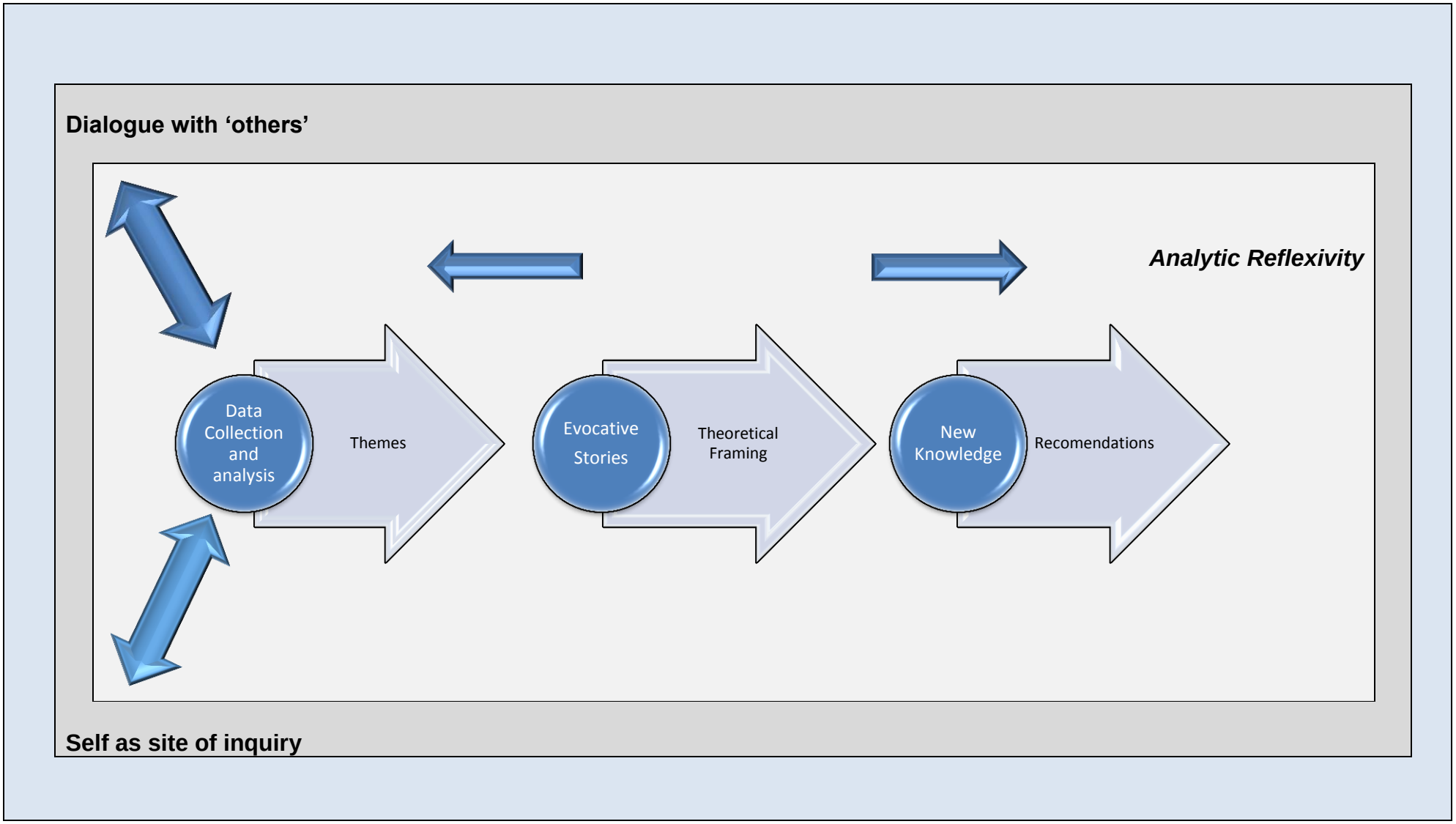
Ellis(2004 p.195) Evaluative Criteria	Anderson (2006) Five Characteristics
1. Do the stories evoke reader's responses? 2. Do they open up the possibility of dialogue, collaboration and relationship? 3. Do they help us get along with each other? 4. Do they help us change institutions? 5. Do they lead us to think through the consequences, values and moral dilemmas?	1. Complete member research status. 2. Analytical Reflexivity. 3. Narrative visibility of the researcher's self. 4. Dialogues with informants beyond self. 5. Commitment to theoretical analysis.

Table 3.3 Evaluative Framework for Evocative and Analytical Autoethnography

3.5 Summary

Due to a lack of definitive guidance and the apparent latitude for creativity and theoretical analysis, I have presented a diagrammatic representation to illustrate the evocative and analytical processes involved in this study (Table 3.4). The decision to combine both analytical and evocative elements, was liberating from a 'perceived' need to conform to a more traditional thesis format. Indeed, as my knowledge and confidence grew; the resonant and interpretive qualities the stories afforded added another layer of thinking on the experience of stigma and its connection to practice and the wider cultural context.

Table 3.4 Evocative and Analytical Autoethnography Map Adapted from Struthers (2012 p.101)



Chapter 4: The Stories

Within this chapter I present the 'stigma stories' that have evolved through the data collection and analysis process. In line with the autobiographical elements of the inquiry these are conferred in a chronological timeframe, to echo five decades and as previously indicated the thesis title – *Growing Pains, Growing Shame and* BEYOND. By so doing, it reflects the temporal nature of reality and the notion of past, present and future. The stories are not necessarily written to make for comfortable reading, but when appreciated within this framework of inquiry it is important for a critical pedagogical style of learning. Woven within the sections will be a thread of 'reflexive dyadic' conversation with self and others.

The findings provide a platform on which to share my 'voice', one that has been informed by memory. Indeed, different voices of self are heard alongside voices of others, and for this reason the text is multi-voiced. In line with this thinking Bakhtin viewed voice as a continual state of expression involving both internal and external dialogue and thus always involving the voices of others (Frank, 2005 p.966). This multifarious enunciation resonates ontologically to being human and the inextricable relational connectivity. Relationships convey an existential quality that is central even when one is alone (Heidegger, 1973). This pluralism provides a bridge to connect and link historical junctures.

Clearly, as asserted by Oleson (2008) there are difficulties with the representation of a voice that is inherently connected and influenced by hegemonic forces and ideology. The reflexive dyadic elements throughout are aimed at capturing a generative communicative process for learning. A process that seeks to express voice that is to some degree controlled as it has the capacity to engage in a more "*reciprocal dialogue*", such that may arguably conjure a more sustainable change to existing power relationships within "*research, knowledge production*". In addition to this, there is a possibility of bringing greater awareness to the inequalities that living with a stigmatised identity may evoke (Gready, 2008 in Trahar, 2009 p.11).

Following the story in line with a structure used by Tsang (2000) and Biscomb (2012), I then provide 'sense-making', which also formed part of the process of my perspective transformation. This starts with a presentation of the story followed by theoretical application, but not the kind that provides "*hypothesis testing*", rather an in-depth and detailed discussion (Pace, 2012) of how and why my stigmatised identity evolved, but also a potential conduit for new knowledge (Polkinghorne, 2007). However, you will note that not all of the stories are rigorously linked to theory, as at times this was difficult to do (Ellis and Bochner 2000; Muncey, 2005). It is important to note that the interpretation that I provide in this process may not be the interpretation that you the reader arrive at. This is because we all perceive reality differently and no two people will see the same thing in the story as a result of this. It provides scope for a dynamic quality, such as that which is captured in Freire's

(1972) notion of transformation and is particularly important when a change is required.

Frank (2013 p.145) conceptualises illness as a "*pedagogy of suffering*". The telling of stories related to mental health may provide learners with a truth, within which there is a quality with the potential to restore autonomy. These stories on stigmatised identity as a result of illness stand on equal footing with my professional knowledge and skills as an educator. They engage in a joint venture between the "*teller and the told*" (Bruner, 1990 p.125). This anticipated union may be used within the teaching space, as a catalyst from which students may gain a deeper awareness of the impact of stigma. It is not the intention to present the stories as a recovery transition, one that within sociological writings is frequently portrayed as a linear process. On the contrary for those with lived experience of mental distress, recovery is often not a straight path (Karp, 1997). For this purpose, the presentation whilst chronologically ordered is more organic and may involve moving '*backwards and forwards'* in an ongoing process towards a new position. Also worthy of note, in contrast to Frank (2013), I prefer to see the stories as a 'pedagogy of survival' as the term 'suffering' to me may perpetuate a negativity toward mental health.

Finally, it is important to note, I have been the one who has decided to include certain stories and facets of my autobiography. There are things I could have included but have chosen to leave out due to them being deemed 'too personal'. Despite this, the stories and sense-making from an

axiological perspective have been conducted with authenticity and transparency.

4.1 Growing Pains

4.1.1 My Weekends at St Mary's

Weekends were not like those of most of my friends. I would listen to their tales of fun and laughter - and smile. Yet behind the happy façade was an intense and growing feeling of envy.

How could I discuss my weekends with them?

Surely, they would not understand, nor want to listen?

I felt angry, distant and isolated!

My mother initiated and organised a coach that took parents to and from the hospital. She also acted as an escort for this journey for over twenty years. As a child I would accompany my parents on either a Saturday or Sunday (or both); it was all I knew, was normal routine, but on reflection it was also done reluctantly and with a heavy heart. I would sit in the front seat next to my mother, at the rear of the driver and silently observe the families as they climbed aboard. I would feel a strange sense of anticipation in the air.

As I sit and reflect on this childhood memory, I lose myself in a sensorial moment

…….the journey seemed long, tinged with a sense of dread. A silent observer, trying to understand the purpose of the weekly ritual. Smiling faces hid weariness and pain. The coach rolled on stopping along the road to pick up families. But what was the purpose of it all?

The long path running through the grounds revealed faceless silhouettes stippled along the way. Some were swaying back and forth, others jumping up and down, clapping hands with excitement for their imminent reunion. Vast green swathes and wooded spaces, yet somehow contained. As the coach glides along, one catches sight of a lake that depending on the weather, would either lift one's spirit as it glimmered from the sun's dapples, or was guaranteed to dampen the mood, when the wet English climate ensured it presented as a murky grey expanse. The coach continues to sweep past the adult isolation wards to the left, and to the right a rather majestic looking hall stands as an echo of more opulent times, when it was the residence of nobility. Ascending a winding hill, the vehicle reaches its final destination, halting in front of a clock tower.

A slow walk, down a tree-lined path, leads to the home of many a soul. It is here my formative years were spent. But what was the purpose of it all? Separated, disconnected and somehow very dissimilar to life as was known beyond the large high walls that surrounded this establishment. Peculiarity, contradiction, a micro community far removed from 'normalcy'. We would have to find him, as he liked to hide, his favourite place being a laundry bag. On one occasion he was loaded on to the rather large lorry that then went round several of the wards to collect the washing and was not found until they were emptying it all at the central wash house. He also liked to hide in cupboards; behind the closed door was a warm, dark safe place, where he could crouch and rock backwards and forwards. He had a fascination with water and loved to sit for hours in the

bathtub watching the drips slowly falling from the silver rim of the tap, with gurgles of delight and gentle rocking backwards and forwards.

The clock on the tower displays four and it is time to retreat from this other world. Families step back onto the coach, waving to loved ones left behind. Is that a tear, or the sound of a deep sigh? All is hushed, all is quiet as the group leave on the same winding path that had allowed them access a short time earlier. But it will soon be time to come back again!

My mind relocates back to the here and now, I think to myself, for this ritual that pre-occupied a great deal of time whilst my sibling was alive it was never really discussed, by anyone other than immediate family. Within the reflective dyadic conversation my sibling retorted *"……nobody ever went to see him. I mean that was one of the things that I remember as a teenager. I used to think well why doesn't anybody come to see him? Why?"*

"…it was almost like he wasn't there, like he didn't exist, because they did not want to have that conversation with our parents or with us about him. That was their way of coping".

Me - *"he never figured in any conversations by anyone other than us"*

Sibling *– "nobody ever went, nobody ever, ever, ever, ever went to see him!..." and I can remember pondering on that and thinking why is that?*

The dyadic with my sibling provided the space and opportunity to reflect on our childhood. What really stands out is we as a family never really discussed the situation either. Were we silenced due to others not wanting to listen? This stifling allowed us to carry on and go through the motions, without any critical awareness of the situation. It was just who we were, an acceptance of a situation that perhaps many would not have tolerated.

Sibling - "*I think for me it was a normality. I know now as I reflect back, the situation our family was in was not ordinary, but at the time I just accepted it as part of being in our family"*

This is also a story of an emerging childhood identity, living with a sibling who had been removed from the family home to reside in a large institution, which from memory was a rather curious, if not foreboding place. As a child much time was spent within this system, and the above vignette portrays the journey that I made with one of my parents every weekend for many years. It was the weekly ritual that was all I knew, but began to dread and disassociate from. This routine was an integral part of my being and a symbolic orientation to how I viewed the physical world. According to Sack (1997) a human is "homo-geographicus", in the sense that an environment becomes a site of central importance. The way humans connect with space and place has a powerful influence on identity. The institution according to Sack is a 'thick' place within which the discourse of the other had led to these formulations. Furthermore, the childhood experience of the weekend routine left a "*symbolic residue*" as I

matured (Giddens, 1991 p.39). This leftover feeling was one of the need for containment, or the requirement to isolate and separate individuals who were perceived as different. On reflection, at this time family life in many ways was in utter disarray. ***Sibling*** - *"when you came along our family was in absolute chaos"*. However, the routine that seemed to solidify and hold it all together was the weekend at St Mary's.

A further striking insight revealed within the dyadic related to how our perceptions of that time were different, that we as individuals within the family unit recalled the memories, ones informed by our age and the unfolding nature of our own realities. But now, through this encounter we were able to move to a mutuality in our understanding, one that had the power to unite these separate worlds through an empathic resonance for the mix of feelings that the conversation evoked.

Secondly, this is a story of containment, or the institutionalisation of those with disabilities who were viewed as 'different' or with a sense of otherness or *dissimilitude*; the need for society to separate, remove and contain otherness in places away from public view, a 'therapeutic community' that provided care and a 'safe' space within which to isolate and control otherness. This could be seen in the strict sex segregation which was very evident in the grounds of St Mary's. The men and women were housed on quite separate grounds within the 'colony'. They were denied a dimension of being human and not allowed to reproduce, for fear

that this would pose a threat to “racial purity” (Humphries and Gordon, 1992 p.102).

Families, whose siblings resided in these places, would often have to make “*long and arduous journeys to get to them*” (Humphries and Gordon, 1992 p.16). For many this would involve more than one bus, which would often be the case as the institutions would be located on the outskirts of the community. As a child I felt a combined sense of dread, but also comfort as I sensed the affinity through adversity amongst the fellow coach passengers.

Within the confines of the institution, the reality was that this was the residence of many who had lived here all their lives as outcasts of society. They were hidden from view in this palace-like space, 'a microcosm' of 'otherness', co-existing alongside 'normal society'. Out of sight, out of mind! ‘Safe’ within the walls and structures that contained them was Bentham’s utopian vision of Panopticon in all its glory, but arguably a vision that had turned into a controlling mechanism (Foucault, 1991).

This is a story of adversity, both individual and collective. Through young eyes, I saw much from an early age that many in society at this time would have perhaps shunned, due to fear or intolerance, which in turn made me feel that I was different. Many of these feelings were deeply internalised and the memory of the weekly ritual ingrained within my psyche. My sibling had a difficult life, something I witnessed frequently,

but this also impacted on my parents who struggled to understand the behaviour, the laughter, the tears, but most of all the internal world of a child who never uttered a word. His emotions were released with an agitated physicality that was raw and vulnerable. Twisting a shred of paper repetitively between his thumb and forefinger, gaze fixed on this as he rocked backwards and forwards. Grabbing a cake from the hands of a man just about to devour this tantalising mouthful and crawling under a table to delight in this himself to the utter astonishment of the victim and embarrassment of our family. My most vivid memory was of his ability to 'vomit at will'. This was usually saved to projectile over those he liked the least. As a child witnessing such behaviour left a confused state, one that accepted him for who he was, but another that felt angry and resentful but also different and disconnected from the world. This hardship and 'weeping silence' could be seen on the faces of the other coach passengers, who all had their own story to tell.

So- how could I share what I did at weekends with my friends.

Why?

"Why would they not listen, why would they not hear?

There appeared no interest, when his name was uttered!

Joined by blood, but a distance between them.

A burden that they did not want to share".

4.1.2 A Moment for Oneness

Both my parents became involved in charitable organisations and activities that aimed to provide support mechanisms for parents of children with learning disabilities. This consumed much of their time during the week, between work and family duties, which resulted in little space left for much else. So as a child the majority of my formative years were shared in the company of those society would appear to have shunned. The discos were rather curious events, 'normal kids' alongside 'abnormal kids', yet at the same

time it was a shared space for all to unite in a moment where the boundaries of 'normalcy' and 'abnormalcy' merged leaving a temporal moment of oneness and a sense of equality. On reflection, these experiences fostered within me from a very early age a deep empathy (but also a heightened self-consciousness) and appreciation of difference of what society may perceive as 'otherness', but with an ironic ambivalence attached. A perception so strong that in previous and current times is still influential in demarcating and confining this notion of 'otherness' within 'safe' 'containable structures'. I did not dread these events as I did the weekends.

In the 1960s one of my parents in association with other parents founded a local branch of a growing national charity, alongside a play group at a local community centre. This group was set up to essentially serve two functions. Firstly, to provide a safe and 'accepting' place for children to learn through play. Secondly, to function as a supportive mechanism for parents to gain support and advice. At this time parents often struggled in isolation to get any guidance, due to this group historically being viewed as a lesser priority (Humphries and Gordon, 1992).

One of the organised events was an annual Christmas Fayre……..again I begin to conjure the memories of this in my mind's eye.

It was a Saturday morning at the end of November and I awoke.

"What time are we leaving?" I shouted down the stairs.

"Your dad will start loading the car up soon" mom replied. In the hallway were many boxes that were full of crafts and curios that my mother had either made, collected or had donated. One of the most popular items was the 'crocheted doll toilet roll cover', but there were many other things, such as frilly coat hangers and peg baskets. A canal boat holiday in 1977 had been the inspiration for mom to try her hand at canal boat art, which involved adorning wooden spoons and brass objects with bright floral designs.

Once the car was loaded we were off to the local church hall to begin setting up. I ran through the door and skidded across the dusty parquet flooring, much to mom's annoyance. "Do you have to do that – here do something useful and give me a hand setting up the stall". "OK", I said somewhat deflated as I knew that in another couple of hours the hall would be bursting with people all flocking to get a bargain. "Never mind" I thought to myself "I'll do what has been asked and as soon as my friend arrives we can go off and do our own thing". This usually involved going on the stage and watching the events from behind the curtains.

"Once you are finished here, you can go to the kitchen and help bring the tea round". The kitchen was a hive of activity and merriment as other club members were preparing refreshment and sandwiches for all the helpers. By this time the queues of people had begun to form outside, some peering in through the windows, trying to decide where to make their way to first when the

doors opened at 2pm. The White Elephant Stall would always be the first place the crowds gravitated towards and buzzed round.

These were happy memories as the people who collectively organised this event appeared to function in an empathic space with a sense of togetherness (Zahavi, 2014). This 'social entity' was a yearly ritual that required commitment and a collective of joint values, the uniting thread of having a child or sibling with a learning disability. Arguably, the mutual co-operation served as a protective function and for support (Goffman, 1990b). Unlike my visits to St Mary's, I looked forward to this annual gathering and would enjoy the free feeling I had running round the large hall and sliding across the parquet flooring. If I were to reflect on anything negative, it would be my growing awareness of general members of the public and the tendency of some to stare at those who appeared different.

My parents' childhood was before and through the Second World War and asylums functioned as total institutions (Goffman, 1987). Both from working class backgrounds, they lived through turbulent times, knowing what life with austerity was like. Being weak or a perception of such was not something that figured in their stoical constitution. Their historical evolution was influential in the development of my own meanings (Bruner, 1990). I grew up in the 1960s-70s when attitudes to many things were changing and arguably becoming more liberated. However, this was not the case when you turn the gaze towards psychiatry. Stigmatisation,

discrimination and non-respect for the human rights and dignity of mentally ill and disabled people remained very prominent.

4.1.3 The Childhood Secret

A combination of these early childhood experiences led me to often feel fearful, I became quite inward and the internalisation of these fears manifested in self-destructive behaviour from around 11 onwards. As I contemplate this, my mind drifts to such time.

I was sitting round the kitchen table, it was Sunday dinner time. My sibling looked over and in jest told me I had "tree trunk legs". This innocent comment was like a slap in the face, one that I did not recover from. This supposedly jovial moment sent me spiralling into a secret lonely world, where I co-existed with food. I began to deprive myself, it felt good and even better when the scales revealed the weight-loss. It became easy to deceive my parents into believing I was eating, when really very little was passing by my lips. My breakfast was usually disposed of in the bin and the sandwiches for school were hidden in my wardrobe, then on my return I would get rid of them in secret while no one was home.

After school one day I returned to find my mother looking very stern and placed in front of her on the table were the sandwiches. She had found them in my covert hiding place and was furious. After this, I was made to sit and eat every meal at the table. Mom also went to the school and revealed my secret to the teachers. I remember vividly to my total

embarrassment and shame, the deputy head visiting my classical studies lesson. She requested I step outside and began to quiz and lecture me on the perils of dieting. Being in the limelight became uncomfortable, it felt as if there was a telescopic lens directed at me from a watchtower high above. I resisted any encounters and if I was approached would usually avert my gaze to the floor and be economical with the truth about what I had eaten. The weight loss continued until the threat of being taken to the doctors made me even more desperate. "What was I going to do?" I thought to myself. Then my mother sat me at the table and placed in front of me several peanut butter sandwiches, alongside a large glass of milk. "You had better eat all that!" she sternly uttered and sat the other side of the table, her gaze fixed on my every mouthful. I ate them all but on leaving the room felt the rising angst that was too intense to bear. I had to get rid of this food whatever the cost.

Whilst this is the story of the beginnings of an illness trajectory that was to run for many years, it is also another story that connects to a ritual, but this one was a very private, secretive one. Trying to make sense of self, whilst at the same time keeping a secret from both family and school, for what might be perceived as my 'vulnerabilities' (van Manen and Levering, 1996) or *'inchoate feelings*' serving to lack the vocabulary to discuss such (Karp, 1997). It is the continuation of the notion of dissimilitude beginning to be turned inward in the psychic structures of a young girl's selfhood. One that continued to nurture adversity, through

coping mechanisms that involved destructive habitual behaviours that were injurious to health.

It is a story of institutional structures, but rather than the asylum, this being the family unit, the school and how these functioned to control the behaviour of children through parenting and education (Foucault, 1991). It is the self-conscious fear of being in the gaze of others or as a site of observation (Schwam, 2011) and how one may then be perceived in terms of 'normal' or overcoming 'abnormality'. I also consider how my other sibling was treated by the teachers due to their apparent differences and reflect on our dyadic connected to the impact of this:

Sibling *- ".....at school....the head injury and all that...they didn't treat me too good, the teachers did not bother with me, it was ridiculous.....just kept saying I was 'thick', 'stupid' ...'couldn't be bothered'".*

Me *- "How did that make you feel?"*

Sibling *- ".....Oh terrible, left out and everything.....it's, it's gone now, but it was difficult....almost started to believe it and given up, just given up trying".*

So it connects back to a need for confinement of behaviour, but this was very inward rather than the public containment that St Mary's provided.

This story captures the fragility of childhood, trying to make sense of self in relation to the world and the context within which I resided. Within this fragile self a rising impression of fear that impacted on identity. A retreat into a world that was hidden from family and teachers, resulting in the beginning of a journey that would be long and painful. The site of surveillance became internalised (Burr, 1995).

4.1.4 Hidden Ritual

"The Hidden Ritual"

Over and over the cycle repeats itself

Hidden from view, behind closed doors

Hushed, a harmful secret not to be spoken

Vicarious emotion silenced with every mouthful

And the years pass by, when will it stop?

It's a Saturday afternoon in 1978, I am 13 years old. "See you later", mom shouts as she shuts the door, leaving to visit my brother in the institution. "*Great!*" I think to myself and feel a surge of excitement as I hear the car door shut. Dad is driving her to the coach station, then stopping off at the library, so I have the afternoon to indulge myself in my secret pastime.

I go to the kitchen and begin to ferret through the cupboards, always taking great care to navigate my way through the biscuit and cake tins, fridge then pantry, so as not to leave any evidence of my having been there. Surrounded by my 'contraband', I sit quietly and begin to work my way through it all. Nothing mattered in this moment, it transported me to a self-soothing space where life was suspended and I could forget my fears, as I feasted on my guilty stash.

The clock ticked with every magnificent mouthful, until I could no longer go on. Reaching for a large glass of water, I would drink then sit feeling a strange stirring of emptiness, a vacant moment before the storm. A cocktail of emotions came rushing into my head and I knew it was time to move fast to rid myself of this painful torrent of panic.

I steal away and lock myself in the toilet to purge myself of it all.

It is here I will spare you the full details. How could I describe to you a moment that was so primal, so raw, yet soothing; intoxicating, whilst at the same time one that made me feel separated from the world, different but not in a good way. What I will say is following this hidden ritual I would feel immense relief, such that transported me to a place where for a short time nothing mattered, at least until the next time, which was not too far round the corner.

As the years passed by the ritual that started with ease became more burdensome and was clearly taking its toll in many ways, not least my physical health and school work. What had begun in innocence became more frantic and

the comfort of the purge turned painful, tiring and filled me with remorse. I could not live without it, but it was becoming increasingly troublesome to live with, but who could I tell? Certainly not the teachers, they had already given me a hard time about dieting the year before, my parents had enough on their plate and my friends would have thought I was 'crazy'. Therefore, it remained hidden, contained within my secret world.

This is a story of disconnection from the world or the separation of self from full being and experience (Giddens, 1991). However, this separate identity of self cannot be seen as unique; rather it is "the self as reflexively understood by the person in terms of his or her biography" (Giddens, 1991 p.53). From a very young age I had been aware of the need to conceal otherness or a reality that has the potential to disturb the status quo.

It is also a story of the containment of difference only in this instance the dissimilarity was directly related to my feelings of self and the need to enclose these through the ritual. In this case the succour was food and copious amounts of it in order to bury the rising angst and then purge at the point of this emotional crescendo to ease the disquiet. Porter (2001) asserts the importance of viewing the self as a crossroads for society, a microcosm within the wider whole. Thus, with institutionalisation and the containment of difference this may be seen within the internalised shame and a containment of self; steadfast cognitive structures that conceal the shame from self and others; a protective function serving to isolate difference.

It is the story of a disconnection from the world and retreat into a childhood psyche. A disconnection on many levels, from the family ritual but also society (Karp, 1997). It coincided with the discontinuation of my weekends at St Mary's, and my journey to a very confined public sphere was now a sojourn into a very private and destructive self-harming behaviour that at the time I had no awareness of. It was like the ritual literally "swallowed up" any anxiety that had developed; "*rising anxiety tends to threaten awareness of self-identity*" (Giddens, 1991p.45). This is because an awareness of one's self becomes veiled.

As a child, the engagement in these concealed destructive habits were a way of being able to detach myself from my angst, or as Kierkgaard (1967) would liken to dread, to acquire snippets of snatched calm. It is the story of a deep and growing sense of guilt and shame, the latter weighing heavily on this self-identity "*because it is essentially anxiety about the adequacy of the narrative by means of which the individual sustains a coherent biography*" (Giddens, 1991 p.65). However, the former has the ability to impact on self-identity on a more unconscious level.

This story is of fear and the need for secrecy in order to avoid any parental or institutional disapproval. Secret derives from Latin secretus: "*separated, set apart, and hidden*" (van Manen and Levering, 1996 p.12). In the solitude of the weekend was an unseen existence that co-existed alongside a multitude of the *"manifest realities in which we live*" (van Manen and Levering, 1996 p.8).

From both an ontological and epistemological perspective my emerging self-identity had become trapped in a void of self-revulsion, and my own hidden mark of shame. It was as if time had stopped and the only vivid memories related to the ones above. As Giddens (1991) would assert in relation to one of the existential parameters, my continuity of identity had been interrupted; control but out of control contradiction. Van Manen and Levering (1996, p.4) question the relationship between secrecy and inwardness and give consideration to the meaning of self; through the experience of keeping a secret, they question whether this results in *"a closing off of self"*.

This is the story of a growing sense of guilt and of disruption through illness of identity. During my emotional crisis I had no "*ontological security*" (Giddens, 1991 p.38). For a child arguably this is something that evolves as one grows, so I was already wavering but as a teenager I became entombed in this existential darkness that was both suffocating and stunting. My distress was hidden and it was a secret that I was not able to share with anyone for all of my childhood years. At this time it was a way of coping with my feelings and emotions. I did not think of it as a 'mental illness', rather a response to a situation that I was not comfortable in. Ironically, I believe I did not reveal the habit as I did not want to stop; it was my solace from a difficult situation.

Backwards and Forwards

Backwards and forwards.

Such solace in that moment.

Time suspended within eternity

It soothes, it calms with its repetitive motion.

Forwards and backwards.

The energy raw and unleashed.

With destructive capacities to make one weary.

Behind closed doors it moves continuously.

Stopping occasionally for fear of being discovered.

4.2 Growing Shame

4.2.1 Forwards and Backwards

The year is 1984 and I have not long turned 19. A great deal has happened over the last few months. I have finished college, started pre-Nurse Training, but also tried to take control of the secret rituals, prompted by a television documentary I watched about a condition called 'Bulimia Nervosa'. It was quite by chance that my eyes and ears feasted on this programme, it drew me in, and I was hanging off every word that was spoken. "I was not alone", I remember thinking to myself, "There are others who are the same as me!" This felt reassuring, but at the same time the message being delivered was horrifying: STOP or you may KILL YOURSELF! I STOPPED, but was not prepared for what was coming.

Complete inner turmoil came into my life in full torrent. It smacked me in the face with such force, it knocked me down and the next few years I was left dazed, moving backwards and forwards and forwards and backwards trying to make sense of it all.

During this time I was drawn in more ways than one to psychiatry. The angst referred to above led me down the road to the psychiatrist's couch, whilst the other a little later ventured into psychiatric nursing. Quite a contradiction when I reflect on this now. This created within me two very separate identities, one that I went to great lengths to hide and one that was the public façade or my professional identity. However, at that time this did not make for a happy union. I struggled on a daily basis with intense crippling, exhausting fear and the exigency to keep on going, whilst simultaneously being overwhelmed with life. The rituals still came and went as a way of coping but were not as frequent.

I had spent a greater part of my childhood visiting an institution and now I was undergoing my nurse training in another. There were many similarities; indeed, both were rather grand structures, set within acres of land, separated from the world outside by tall walls that contained those who society had shunned. As was the case with my brother, many had spent the majority of their lives within the walls.

It was during these years that I became more fearful of my 'illness', the possible exposure rendering a feeling that I had more to lose now. One of the dilemmas was that the stigma of mental illness was very evident among the attitudes of the health professionals and this only served to intensify my apprehension. How would I be viewed if anyone knew I was experiencing mental distress?

Some of the staff in the 1980s appeared to be very institutionalised and there was a definite culture of 'them and us'. I would sit on the one side of the fence and be party to these attitudes. On the other a need to hide, but arguably able to have greater empathy with the 'patients' as they were referred to in the hospital setting. I could identify with what some were going through, but I had to maintain professional boundaries. This was difficult, especially when some would say to me "you don't understand what it's like", because I did.

So at work I was one persona and at home another trying to recover, but this was hindered by a self- and societal-enforced dichotomy. Once I qualified, I moved out of the hospital setting and by the late 1980s there were big changes occurring with the proposed closing of the institutions and a slow move to more community-orientated services. However, this discomfort with the two personas continued to bear a heavy presence.

This is the story of the power of the institution. Foucault (1988) argued that in the 18th century a mass policing of the so called 'mad' occurred. The asylums

replaced leper colonies situated on the outskirts of a community, an act of social control to absorb the poor and those deemed as 'deviant' in some way. Many historians claimed this historical juncture was a point where those perceived with such dissimilitude were separated, discriminated against and subjugated (Macdonald, 1983; Scull, 1982; Foucault, 1988). Foucault asserted this "great confinement" was a pan-European phenomenon, the powerful elite harbouring attitudes towards 'degeneracy' and 'difference' and perceiving such as an 'ulcer' on the 'body politic'. However, Medical Historian Professor Roy Porter (1993) states this was not the case for England. He contends, it was not until 1845 that institutional imperatives fuelled by utilitarian principles, stipulated that every county have an asylum. Great strides were taken to build rather grand and ornate receptacles in which to house all that did not conform to the moral fabric of the day. Having spent my childhood in one, I was now drawn back within the walls of another to undertake my nurse training. Within the area of psychiatry Foucault's (1988; 1991) research and writings have led to potent debates on the power of the institution and of particular forms of knowledge that serve to create and shape our subjective awareness of reality, the ethers of power and the strong miasmic potential of this force. Foucault did not attempt to define power; rather he argued it to be at all levels (Howell, 2013).

Similarly, Goffman (1987, 1990a&b), was a very radical critic of the structures that contained such difference and the external stigma that appeared so influential in the weighing of a heavy societal presence. He also paid close attention to moves to internalised stigma and how the wider discourse

becomes internalised within the individual psyche, which then serves to influence the way someone thinks and feels about themselves. The latter, to me, is moving more into a constructivist mode whereby the cognitive processes are also at play in further serving to create someone's lived reality.

Therefore, there is a further tale of authoritarian institutional structures, coupled with the rising feeling of shame and the need to hide the side of self that would be perceived as 'other'. The stigma associated with mental illness was now very apparent and nowhere more so than within the system, fuelled by the attitudes and language used by the caregivers.

As previously indicated, van Manen and Levering (1996, p.142) provide some interesting contentions on the keeping of secrets and whilst in their discussion the focus is on childhood, they suggest that the doing of such leads to a "*splitting of inner and outer self*", or a *bifurcation* of identity of self. Smith (1990 p.25) uses the term "*bifurcation of consciousness*" to refer to "voice" or identities that are contained within separate spheres, a result of inherent power dynamics. Two separate consciousnesses existing alongside one another, which may become burdensome for the person who has to uphold the difference, with the potential to instil feelings of shame or guilt. The above feelings were inherent qualities within my stigmatised identity.

Finally, this is the continued story of the stigma caused as a result of mental illness, along with a maturing identity that brought forth a growing awareness of the self-destructive behaviour and the gravity of a situation in which I may be exposed. Despite the condition of bulimia affecting many, it is a silent condition that remains hidden, not least due to a fear of being labelled (Stavrou, 2009). Distress and illness can create a process of bifurcation and for myself this stemmed from fear and shame of the 'other'. With the disorientating dilemma came an increased awareness of the stigmatised other/identity and how this had created a block to full authenticity. With this newfound insight came a need to try to take definitive control of the addictive habit.

“Invisible”

I sit and face the stranger, who cannot see me,

Their eyes fixed on the notes that they hold.

I talk with a sense that they cannot hear me.

Negative perceptions serve to muffle my voice.

Would they hear if I screamed? Alas I think not!

This would only serve to heighten this bias.

My invisibility perpetuated by this invisible force.

4.2.2 My 'Pseudo-Medicalised Identity'.

Behind closed doors, my heart is beating fast, as I stare at the document for what seems like an eternity. I begin to digest the narrative content which transports me to a previous moment and memory:

….it's a sunny afternoon as I make my way to the appointment. Ongoing health niggles have resulted in repeated hospital visits, but I am feeling OK! However, as I enter the space I begin to feel a degree of trepidation and unease. I wonder to myself if it will be like most of the others experienced - short, impersonal and leaving me feeling a degree of dissatisfaction.

The waiting room is pretty much like any other, and I watch the goings on around me as I bide my time until my name is called. Today there is not much of a delay, I am summoned fairly quickly and led by a nameless person into the sterile medical space. "Hello", says the man sitting at the desk, his head down looking at the paper work. "Well what can I do for you today?" Then he raises his head and moves to make eye contact. I politely recount the reason for my visit and at this point he stands and requests to look in my mouth, and while doing this he asks "….have you put on weight recently?"

I replied "…well actually I have over the last two years or so, but do you mind me asking how can you tell if someone has put on weight by looking down their throat?" His eyes fixed mine with a rather curious expression, but offered no

answer to my question. This left me feeling somewhat perplexed. He muttered before I departed that I should expect to receive a follow up appointment within three months: six months lapsed and I was still waiting. I chased this up.

*Within the letter, something immediately catches my eye "……**she admits to putting on weight gradually over the last few months and has started dieting which is helping her**". I was a little taken aback, and on leaving decided I would ask to review further correspondence on my health.*

I begin to read the 'historical artefacts'…..only to have my long-held intuitive feelings finally validated. Snippets of the narrative immediately caught my attention - for example:

"…..this anxious member of the nursing profession"

I mull over this statement. What qualifies as an "anxious member of the nursing profession"? I think to myself. In fact I don't think I had said what my occupation was. What bearing did it have on the consultation? I say to myself "nursing as a profession is arguably a stressful occupation", so there may be times when it causes an appropriate degree of anxiety.

"…..I have advised this over anxious expectant mother"

Well! not sure what you have to do to qualify for such a title? I was definitely expecting my first child when this was written, so I guess a certain degree of anxiety may well have been warranted. However, I did not think I was presenting in a nervous way, and the topic of anxiety never came into the conversation. Why would such a sentence be written and what significance does it have?

"…..it may be that …….taken at night would satisfy everybody's requirements"

*Well, I am speechless now as I reflect on the "everybody's requirements" comment and this one stings quite sharply. Hmmmmm….. not sure what to think really, one thing for sure is I feel slightly humiliated as I sit and gaze at the words before me. Surely, it is what should be deemed as 'my requirements' as the patient? Why should everybody's be of concern? Do they think I am a nuisance? There is an intolerant tone and my initial interpretation was that there was a degree of ridicule. I continue to read and the words were like a slap in the face. "****she's becoming increasingly anxious about her self-monitored "hypertension"****…. Getting more heated under the collar ……..I am speechless and now rather numb.*

What the narrative revealed appeared to echo verbal manifestations that had been articulated within my previous medical encounters.

"…You gave your mom a hard time when you were younger"

or

"…I would say you are someone who is rather susceptible to stress: wouldn't you?"

to

"..you've had some nice things said about you!"

This is a story of veiled power, knowledge and dominance that was acted out within the 'therapeutic encounter'. Subtle invisible processes were shaped through the discourse that was either written or spoken. From the perspective

of social constructionist proponents what the health professionals wrote would not be viewed as valid interpretations of my internal reality, rather the comments were utterances of the "discursive culture" the medics reside within. My 'identity' within the discourse has evolved from a wider cultural reality (Burr, 1995). The way individuals are portrayed is important as negative interpretations only serve to have potentially devastating effects in terms of stigma (Baker *et al.*, 2010). Furthermore, the intonation was one that implied my condition was 'self-inflicted' (Bannatyne and Stapleton, 2015).

Giddens (1991) provided insightful discussion on the biomedical model that governs western medicine and influences healthcare. He cites its enduring dominatory presence within cultural practices and the knowledge base that medicine is situated in. The biomedical discourse conveys an impression of authority and hegemonic force that enables the health professionals to command a level of power that has the potential to silence the voice of the patient, override and marginalize indigenous knowledge or the voice of the patient.

In the position of being a recipient of health services I was "*a pretext for a round of orations, narrations and disputations*" (Atkinson, 1997 p.328). But arguably, these consultations were snippets of time situated within a fuller context that was not fully appreciated or sufficiently captured. Similarly, it may be deemed a rather narrow understanding of a whole and much more complex reality. Within and throughout the narrative were *"numerous*

depictions" of anxiety that were associated with different moments in time. They were my anxiety "*circuits of discourse*" from those carers who attended to me. (Atkinson, 1995 in Atkinson, 1997 p.328). Or the emerging "*discursive formation*" which as Foucault contends is the moment in time when this discursive practice derives an individual and autonomous quality, this quality that was anxiety (Foucault, 2001 p.206).

As Foucault (2001 p.56-7) contends, the position of a doctor is intrinsically connected to a complex web containing knowledge competencies, institutional practices and culture that are legitimised within a legal and ethical framework that conveys the 'right' to practice. It is one that acquires a privileged status, to such a degree that they may be perceived as having thaumaturgical powers. Therefore, medical discourse is one that may only be the product of a medic's role, from within the institutional setting "*a place of constant, coded, systematic observation, run by a differentiated and hierarchized medical staff*".

Kleinman (1988) asserts that within health care, one surprising result of change is that a practitioner's focus deviates away from the actual lived experience of the illness. As a result, the system risks alienation or disconnection of the professional from the service user. What I had read could be described as what Bakhtin would refer to as '*monological*" in form, one that presents as having the final definitive word (in Holquist, 2004; Frank, 2005). Interestingly, it has been asserted this is a regular occurrence within institutional settings such as the hospital and within the doctor/patient

relationship. This is a powerful force in medicine where doctors are trained to offer definitive discourses. An outcome of this practice, as was the case for myself, is that one begins to accept it. This highlights the importance of the need for dialogues rather than monologue in order to place both doctor and patient on equal footing (Frank, 2005).

Kleinman (1988, p.xiii) refers to a "*symbolic bridge*" in treatment and the above captures some of the journey over this metaphorical structure and its connection of the self to the wider society. It is also about the attitudes and perceptions that those providing support harbour and how these are nurtured within the health encounter and are mirrored by both the 'Dr/patient'.

The specialist provided the 'diagnosis' or 'iatrogenic' account of my experiences (Illich, 1995). The foundations of my medical identity were laid for the evolution of what I will refer to as a theoretical conceptualisation of my '*pseudo-medicalised identity*', one that matured over the years and continues to have a presence not only within the structure of the medical discourse, but in shaping the therapeutic outcomes, influencing subsequent consultations without the need for me to be present. Kondrat and Teater (2009) indicated stigma manifests in stereotyping. Therefore, was my pseudo-medicalised identity a form of 'medical stereotyping'?

My existential being was rendered in writing, but I had been unaware of this unfolding persona that was hidden and contained between the worn, frayed folder, only revealing itself to the professionals when I attended appointments. An interesting paradox to reflect on … there were essentially two people in the consultation. So this is another tale of bifurcation of identity, the one in discourse and the embodied persona that sat before the doctor. How could it be that this invisible 'other' could be so completely influential in shaping my 'pseudo-medicalised identity'? Having had time to interpret meaning for myself I could not identify with this 'other'.

From analytical reflection on this I have come to the conclusion (and you may also decide) that this identity was the creation of a collective discourse arising from a medical dialogical space and psyche. The medic and the discourse may create an "*artificial binary*" (Rowland, 2015 p.2) between what is deemed normal and abnormal. Thus, an insidious process was occurring for both disjointed but also collective formations and perception of my identity. Indeed, I was unaware of this alter ego and had no conscious agency in its evolution and management.

Furthermore, my medical records were contained within what Foucault (2001 p.57) refers to as '*documentary field"* containing the 'observations' that then provided information for subsequent doctors with whom I came into contact. From a feminist perspective the articulation of me may well be perceived as having misogynistic elements with origins in 19th century psychiatric

discourse. An interesting consideration to ponder, one that links to feminist historical insights is that during the 19th century 'medical men' had a tendency to view women as more susceptible to the 'exaggeration' of emotion and thus more vulnerable than men (Showalter, 1987). It may be argued that the voices of those that went before us reverberated within the discourse that my eyes surveyed. My anxiety appeared to have become the fundamental thread within the tapestry of my 'pseudo-medicalised identity'. Feminist sociological thinkers argued that patriarchal authority seeks to label women (Showalter 1987; Appignanesi, 2009).

Whenever I entered the 'healing' space the feelings manifesting from the sub-conscious projection of this identity began to intensify. I felt a deep sense of guilt and shame every time I entered the 'healing space'. This entwined with anxiety served to instil a fearful nature which reduced my ability to think in a rational way (Gilbert, 1998). Kleinman (1988 p.161) asserts that caregivers should have an awareness of stigma and shame, however this did not appear to be the case in my experience. Charon (2008 p.30) argues emotions such as shame *"erect the most unbreachable divide between doctors and patients"*. This in turn may serve to block 'true dialogue' as both parties 'collude' with the emotion. Thus, if someone finds it difficult to verbalise symptoms due to negative feelings this then may result in the doctor being embarrassed to listen, placing significant pressure on the doctor/patient relationship and highlighting the importance of relational reciprocity and how it may not always have positive benefits.

Van Manen and Levering (1996 p.145) state"….*one feels shame when judged by other people for the fault that one agrees is a fault"*, and they assert shame does seem to align with fault. This was definitely a feeling experienced when taking the first steps for help at the age of 19 and has continued throughout the next few decades. Despite having this apparent fault, the caregivers never actually verbalised what they then went on to record. They would read my notes and contribute to the identity formation but not share it with me. So again the experience was shrouded in secrecy that again led to splitting of self (my perceived self and the caregiver's perception of me). Equally it felt humiliating as if I was being looked down on, degraded by the medic's responses and the power yielded within the unequal encounter. I felt tainted, my identity contaminated by this "*insidious form of control"* (Zahavi, 2014 p.227).

Giddens (1991) stated that institutions are spaces for suppression as opposed to self-actualisation and empowerment. The dominant medical discourse does not allow for the voice to be heard. Arguably, I had become marginalised within the discourse by the dominant power. Within this space my "pseudo-medicalised identity" took precedence. I sat before them in the consulting space but was invisible as the writings had rendered me so.

My voice was silenced and whenever I plucked up the courage to assert myself this only served to be seen as part of my 'over-anxious' constitution. Richards (2008 p.1719) argues that there is this assumption within medicalised narratives that clients should be "*talked about, but should themselves remain*

silent as if they do not have anything to contribute". This led to a slow insidious erosion of my confidence and ability to be assertive. Arguably, a side effect of an overly authoritative environment *"where self–assertion is equated with disobedience, attack, sin"* (Fromm, 1975, in MacLeod, 1981 p.54)

Within the therapeutic encounter, I was left feeling stripped of dignity and any self-worth. Robinson, Kendrick and Brown (2003 p.66) assert dignity is not given, rather develops from a relationship. Within the majority of encounters I had, there was a discontinuity of care that potentially presented as an impeding factor for any dignity to emerge. They further poignantly state that central to the promotion of dignity is empathy, which may serve to allow those within the therapeutic encounter to realise that being 'ill' does not confer the status of "*a stranger or an alien, totally different from the other".* In my case I would argue this was sadly lacking.

It was as if in their eyes I was not me, rather an entity or other that then impacted on my self-perception and identity. Richards (2008 p.1717) states "*the rendering of people as other (not like the norm) comes at a cost to humanity*". This experience, that perpetuated from the time of seeking help, cost me much loss of authentic self, a shutting off of my true feelings for the fear of these being further medicalised. In addition linking back to the research on microaggressions, the experiences contributed to the internalization of stigma and left me feeling invalidated, shamed and inferior (Gonzales *et al.,* 2015).

Furthermore, it appeared my 'othering' changed throughout the historical timeframe to correspond with life junctures. Thus, I began as "a girl with an intractable problem", to "*an anxious member of the nursing profession*" to "*over-anxious expectant mother to be*". I am now waiting for the pseudo-medicalised alignment to the next life juncture. This othering is certainly not a new phenomenon and those with 'mental distress' have a long history of this as discussed throughout this thesis. It has been asserted that people are reluctant to seek treatment for fear of being labelled and discriminated against (Thornicroft, 2008). As a teenager presenting for the first time, I held no preconceptions. However, over time I became increasingly apprehensive of entering the 'healing' space for fear of being judged. Subsequent visits would always be accompanied by such uncomfortable thoughts and feelings. Stigma interferes with treatment and support which in turn is a significant public health concern (Wang *et al*., 2007, in Rusch and Corrigan, 2013). The narrative captures a discourse that is arguably stigmatising and again a subtle undermining of my being. For example "*her self-monitored hypertension*" arguably a further micro-aggressive behaviour (Pierce, 1989; Sue *et al.,* 2007; Gonzales *et al.,* 2015). Whilst I believe this was not a conscious maleficence on behalf of the caregiver, it did serve to perpetuate the insidious presence of a pseudo-medicalised identity.

This led to me believing that I was not worthy of good treatment. I did not challenge the professionals in the early years because of low self-esteem and thinking I was to blame for all that had happened to me and that everything was a result of a somewhat flawed personality. As (Rusch *et*

al., 2006 in Rusch and Corrigan, 2013) state, the emotional response to stigma is that of shame. "Growing Shame"! At times my existential discomfort entombed me within myself and within became a site of intense emotion and feeling that at times thwarted me in my tracks. Goffman (1987 p.285) refers to those in the caregiving role as "servers". This union relies on the client having a confidence in the servers' knowledge and expertise and a trust that they will carry out the caring role in a way that upholds ethical values.

In line with the generative themes is the observation of oppositional forces. The rather curious paradox is that when my consultations related to physical ailments, in the written narrative they always appeared to relate these to psychological causes. Ironically when I now question whether symptoms may be psychological, they only want to focus on the physical. Both are of equal importance, intrinsically linked and when considered from a holistic perspective really cannot be separated.

"An Ode to the Other"

A need to hide, to not be fully me

The fear of being judged, a constant reminder.

What is it you think, when you talk with me?

Can you move beyond your assumptions with

the fortitude to listen, to listen and be"?

There is space for opportunity, a moment for empathy

But, alas it is stilted, thwarted by what you have read.

Pre-conceived ideas have fogged the space and left

a stench of ineptitude.....a stagnant reality,

an impasse preserved for every encounter.

4.3 BEYOND

4.3.1 Theme- board

It is 2013, and I have recently embarked on a professional doctoral programme. Today was the launch of a new module and I was the first to arrive to class, so sat and 'anxiously' waited. After our initial introductions and guidance, I embarked on creating my personal theme-board, using imagery from magazines that held resonance and related to both my personal and professional journey to doctorate studies. The next hour or so was spent mindfully engaged in the process of searching the glossy pages, selecting things that held resonance, to create a visual depiction of 'self'. At first, I felt I had been cast adrift and spent a few minutes with one eye on the pictures and the other on my peers wondering if they were feeling the same way as me. I inhaled slowly, exhaled even more slowly, relaxed and let my intuition guide me.

The photograph above displays my theme-board. Following the event, I began to realise just how profoundly reminiscent the experience had been. I could appreciate that some of the imagery chosen, whilst initially appearing random, held quite meaningful symbolic resonance, which at the time of selection was not apparent. Additionally, it seemed to convey significant phenomenological expression, along with projecting glimmers and more obvious insights into my own ontology. With each new thought I had a sense of an unfolding awareness that was difficult to put into any particular context; it was unsettling but it felt as if there was movement, yet a direction was not yet apparent.

I awoke the next morning from a night where I am unsure if I slept, whether my nocturnal thoughts were waking thoughts or part of a dream, it all felt somewhat surreal! In class the next day the lecturer had through poetry captured her interpretation of my theme-board and recited this in class. I felt a sense of heightened emotion; from this reciprocal process I acquired yet another layer to my story, giving a richer texture to its fabric.

I have since revisited this theme-board many times whilst engaging in this autoethnographical inquiry and it has continued to reveal new insights and "*symbolic association*" with the stories that have preceded this. For example, the cyclical ordering conveys a sense of dynamism and an ongoing process and the Volcano according to psychological analysis represents creation of "*metaphorical dialogue".* The unconscious mind personifies aspects of material culture. It draws parallels with the ideas of "*flow*" by Csikszentmihalyi (1999);

the activity provided space to be creative, but at the same time with a degree of challenge and anxiety, which gave way to enjoyment and a sense of being in the moment. The session provided space for the expression of my individual and the group's collective ideas; it really bought home to me the importance of 'social processes' and how these influence any epistemological developments, along with the spontaneity of the moment (Romero, 1998).

Autoethnography as both method and text within the context of a professional doctorate may be a useful vehicle for the exploration of self along with contributing both cathartic and educative elements (Hayes and Fulton, 2015). The theme-board was one of the catalysts for my 'disorientating dilemma'. Well I had not been able to share my lived experience, and never had from the beginning of the evolution of the stigmatised identity. It was a childhood secret that became a mark of shame that I could not release and set free for fear of being judged or perceived in a negative way.

One particular book by Palmer (2007a) enabled me to be reflexive on some of the discomfort that I was experiencing. For example he talks about the importance of *"educating the heart"* and in order to do this to think about what we are able to bring (inner gifts) to our practice. One question that really struck a chord was whether I felt able to give these "*gifts*" freely. And if not, what was stopping this from occurring?

Palmer (2007a p.27) enabled me to consider what I was most passionate about as a teacher. Well, I have been very dedicated to mental health pedagogy, but always felt a fraud or that I should not be in the role as educator because I had been perceived as mentally flawed for a large part of my life. There was always a tension between two sides of self, a bifurcation that continually buffed against one another in a suspended tension that would not allow for a moving beyond.

This is a story of the beginning of *assimilation* of the elements of identity that had become separated. Through learning and having the opportunity to engage in reflexive activity I have been able to make sense of the situation. It is here that I became aware of 'my disorientating dilemma'. This provided the orientation to embark on my rite of passage to not only undertake a research project but also to move through a stigmatised identity to a place beyond.

This is a story of the beginnings of transformation, in line with Mezirow (1981, 1997), a perspective transformation but also a movement in the perception of self in order to be more authentic in practice. It is also a story of the institutional structures, and reflects a change in the thinking related to mental health that has begun to shift people's thinking into a more collective sphere. For transformation to occur there needs to be a "*resolution of old dichotomies within a frame that accepts both old and new*" (Kegan, 1982 in Daloz, 2012 p.142). Thus, it is a process of integration and assimilation, to merge the two rather than cast out the old. This would make for an

inauthentic position so for full integration and authenticity, it is important to have a merge that moves us to a new position with full mindfulness of the whole situation.

4.3.2 The 'Disorientating Dilemma'.

I am sitting reflecting on the doctoral journey and how it links to enhancing my professional practice.

"There is still a block", I think to myself,

"something that is holding me back from being fully authentic".

"Why have I never been able to share my 'lived experience' in the teaching and learning space…why is there a part of me that holds back?"

This has become what I have alluded to throughout as my "disorientating dilemma", one that has now reached a pivotal moment in the life and every breath of this thesis. There is no turning back as I realise the liminality of the moment from which I will move to a new position.

The literature that provided the context and in many ways the catalyst for the journey revealed that students' learning was greatly enhanced from the 'lived experience'. Not only this, but the negative attitudinal framing toward mental health shifted to a more positive re-orientation. I know this to be the case; as a lecturer who is committed to anti-stigma pedagogy, I invite those with lived experience to come and share their stories in the modules I have developed and lead. I sit and reflect on some of the evaluations that I had received following

such sessions; it is very strong and compelling evidence that the activity has had a profound impact on many.

There would appear to be a need for more research that draws on an academic with lived experience and this could provide a gap that I was able to fill. With a commitment and passion for changing attitudes and a wealth of very relevant experience that had never been revealed, I contemplated these steps and while doing so immediately felt vulnerable. However, as I grapple with my ideas the discomfort or the push to do so has at times felt intense and I have moved backwards and forwards in different temporal moments and with other voices of self in what I can only describe as an existential interplay, the emotions heightened and the feelings driving me intuitively to what felt right.

I think to myself how far society would appear to have moved forwards recently and there is a great deal more emphasis on activities and campaigns directed to reducing the stigma associated with mental health and wellbeing. We have to go back before we can go forward or so it is said. I stand in front of my students, with my professional mask on and feel uncomfortable that this façade hides a deeper authenticity. The following questions preoccupy my thoughts:

"How would I be perceived?
What would my students think of me?
Is it relevant or am I crossing boundaries?
Will it have a detrimental impact?
Will it create negative attitudes?"

It felt risky!

But another voice within retorts "hang on, if we are to trying to 'rid' society of the stigma then it should be fine".

"Are you not perpetuating some of this negative mentality by hiding behind this mask?"

"Surely, revealing the vulnerability of being human can only be positive?"

"Your lived experience informs your practice and your practice has derived from your lived experience".

"How can the personal and the professional be separated?" This reflects what essentially has been and continues to be the dualistic nature of reality.

Chang (2008) refers to others of similarity and others of difference. Therein lies the disorientating dilemma or contradiction as my others of similarity were also my others of difference within the learning space. The joining of these different identities that had become bifurcated on many levels required assimilation, through finding the similitude in the dissimilitude (Wordsworth 2014). But is it not always that way; society would appear to create these 'tensions' or separations of 'them and us'. When I was a child, a service user and a health professional, there was a very definite culture of this, or the need to create this sense of 'otherness'. Across the socio-cultural and historical milieu stigma as a phenomenon has continued to bear a heavy weight, an insidious and powerful presence that holds back more open, positive perceptions individually and collectively, but also the development of caring and compassionate health and wellbeing services.

The dominant discourse shapes and moulds us into a particular way of thinking, a certain state of experience and disconnection from true existential

awareness. My disconnection was through fear, through a need to be seen as ok. The interesting paradox was I always considered myself in youth a non-conformist and a bit of a rebel, or so to speak. On reflection this was a psychic mirage, a veil that allowed the anger within to be contained. Institutions provided the physical boundary that allowed this social distance and now these have gone! These structures were perhaps what enabled us to internalise negative associations to block them out within the collective consciousness. Within the postmodern era these "solid structures" have been replaced by a more "liquid" geography (Gilbert, 2007) where the 'mad' and 'sane' share *"the same bathwater of life"* (Crawford, 2002 p.10). So perhaps the time is ripe for some integration?

Giddens (1991) states this process involves attaining a state of balance between the opportunities that are presented as well as inherent risks. The anticipation of the revealing of some of the stories of my own stigmatised identity did feel precarious. At first the fear of doing such held me back, the feeling being one "*that often accompanies the public revelation of a secret*" (van Manen and Levering, 1996 p.145). Shame is a powerful emotion (Giddens, 1991). I needed to release this secret and the deep shame intertwined with it.

Furthermore, move away from arguably a level of 'dishonesty' (Grant, 2016). I took tentative steps in this direction until there was no turning back. Indeed, it has been 'freeing' from some of the self-imposed oppressive forces to the ones that have manifested through others' behaviours and the discourse that has shaped our perceptions of mental health.

Additionally, there are both educational as well a psychological implications when considering issues of stigma, empowerment, and change or as Freire (2014) might view it, provide 'a pedagogy of hope'. Within my role I place importance on experiential learning and fostering more participatory approaches to learning which draw on experience, reflection, epistemologically underpinned by sociological theories in order to work with a 'social model' in mental health (Tew, 2011; Rogers and Pilgrim, 2014). I hold a strong recognition that students as learners need to relate to the lived experience in the shaping of their learning on stigma. This allows for dialogue to ensure they are not just passive recipients of an essentially didactic learning style and providing opportunity for critical consciousness that may begin to change perceptions towards Mental Health and ill health. Experiential learning reflects the ontology of the learner and assists in facilitating a self-directed learning style (Knowles, Holton III and Swanson, 1998). As Freire (1972) would argue, dialogue is at the heart of communication and fundamental for educative truths.

As an educator studying on the professional doctorate, my disorientating dilemma became all pervasive (Mezirow, 2000) within my teaching, but also on a deeply personal level. I have never shared my story, there are only a few

close family and friends who have knowledge of my lived experience of mental distress. This was all intense during my pedagogical practice when I employed service users to share their experience with my students. I felt cut off from this deep existential learning, as I was unable to tell my story. I have experienced profound fear of being perceived differently, a result of what I believe is due to a deeply entrenched stigmatized identity. This had led to a bifurcation of identity, of two separate selves, the professional who has the knowledge and power and the service user who has the lived experience, but until recently lacked the courage but also awareness of the power this can harness to create an empathic learning space but also a learning tool to address the patient/doctor status quo. The people who shared their stories provided me with the courage and inspiration to share mine in this inquiry.

By the not sharing of my story I am colluding with stigma. It may be gleaned from the previous literature reviewed that students' learning and attitudes are positively influenced through contact interventions and this includes contact within higher education from academics with lived experience. By not being able to share my story I am holding on to a stigmatized identity. The telling will be potentially freeing, but also add insight to a growing body of 'survivor literature' and its potency for *transformational* learning in higher education.

This chapter has presented the findings, in the form of stories, that have then been theoretically connected to illuminate the themes revealed from the

analytical process. Chapter Five will now situate these findings back within the literature.

A Suffocating Silence

Tightly bound, contained and silent,

Beneath these shackles the feelings swell

A need to burst free…and truly be!

The tension presses, gently then with more fervour.

No longer can it hold, bursting through into the open,

An opportunity to now fully BREATHE!

Chapter Five: The Discussion

The intention herewith is to connect the themes revealed within the stories to the literature, situated alongside the wider context to further elucidate their saliency to address my research questions. By so doing, I will provide some consolidation and broader theoretical analysis. This review of the findings also enables further explication of their narrative potential to influence my pedagogical practice within the health and wellbeing context.

Interestingly the term, "*rechercher*" is French for 'to research' and has its origins from a word that means "*to travel through while searching*" (Four Arrows, 2008 p.18). For the purpose of this inquiry, I have traversed in memory through different temporal moments and significant biographical

junctures as well as 'disjunctures', in an attempt to answer my research questions. The stories in Chapter Four convey the themes acknowledged from the data interpretive endeavour, through an analytic process generating meanings or 'truths' that are not only personally situated but it is hoped promote a collective connectivity. It is anticipated that within a shared learning space these 'truths' will continue to evolve in a dynamic interplay, and are thus in a constant process of 'becoming' (Maslow, 1954).

So as I sit here and reflect on question one, I ask myself – *"**so what stories do I and 'others' have to tell about the experience of mental health stigma**?"*

Well to be true to the philosophical position articulated in Chapter Three, there is no one truth. Therefore, the stories convey themes from my own truth and interpretation. It is for you the reader to do your own sense-making and engage in dialogue, to move back and forth towards understanding. However, before expanding the discussion I need to revisit the titles given to each section within the previous chapter. Firstly, the metaphorical term *Growing Pains* relates to my childhood experience. Growing pains in childhood is a well-researched physical phenomenon; here, these pains relate to deep existential ones. The growing pains grew from the seeds planted in a younger self, due to circumstance that then firmly established the roots of the *Growing Shame* that ensued.

Starting out on the Professional Doctorate reignited these buried pains, a state I have referred to as '*my disorientating dilemma'*. As previously determined this position formed the impetus for this inquiry, and its utility in capturing the generative processes that encapsulate reality and a transition to a place *BEYOND*. Generative themes, or the notion of such, are also expressed with the backwards and forwards notion I hope to have conveyed in Chapter Four. To present a "*dynamic temporal"* (Sartre, 1993 p.130), in which the negative attitudes get left behind as more positive views emerge on a personal level but also the anticipated translation of these into the learning space.

This platform has also involved the voices of significant others, including other selves. Indeed, this 'multi-voiced' narrative has in my opinion enriched the stories. The reflexive dyadic with siblings were both emotive and powerful in gathering other views on a reality of stigma. The opportunity to conduct these was a revelation, as we as a family shared things never discussed before and may never have done, had I not embarked on this study. The '*boy in a dark cupboard'* did not have a voice, he never spoke a word in his 26 years of life. Thus, echoed within are 'snapshots' in memory, through my voice and those who were honoured to have known him, held his hand and comforted him when he was distressed.

It has been said that 'meaning perspectives' are usually acquired in our formative years (Mezirow, 2000). Change, according to Mezirow, becomes more problematic if it does not sit comfortably with the recipient's frame of

reference. Well, therein lies the dilemma, for most of my life my lived experience had become a 'suffocating silence' whose firm grip prevented the breathing of my lived reality. Therefore, the sharing of the story has been a freeing process.

I feared sharing my lived experience for multiple reasons that on captious reflection I now see relate to a deeply stigmatised identity, one that has matured over time within the ebb and flow of ideology. A critical pedagogic approach has facilitated analysis of the hierarchies that create a power dynamic, in this case the role institutions and specialist bodies of knowledge have played in fuelling the phenomenon that is stigma. This could also be linked to myself as teacher, arguably conferred in a relative position of power set alongside my students. Yet it is with some irony that a tension or contradiction has been present in my stigma narrative that comes from a position of disempowerment. A voice that has been silenced but as a result of research (Bryne *et al.*, 2013) now has opportunity to speak. The exposing of a vulnerable self may serve to make the students feel uncomfortable and when considered in this way may invoke a sense of threat at my attempt to challenge these deeply embedded power structures. Arguably it is this discomfort that may trigger perspective transformative learning and should not be avoided. So, as stated earlier the stories are ones of *dissimilitude, disconnection, bifurcation, assimilation and transformation.* What follows is further discussion on these, linking them to the wider contextual issues.

5.1 Dissimilitude

By definition this refers to *a difference, or state of being different* (Cambridge Dictionary, 2017).

I have captured within the stories the notion of dissimilitude. As previously acknowledged, it would seem that when adopting a historical perspective, society has always 'othered' those deemed as different. Undoubtedly, this remains the case, when it relates to issues that sit outside how we, as individuals or collectively, have been conditioned to view mental illness. I had a strong sense of dissimilitude instilled within me from a very early age, that emanated from my lived reality and in particular my weekends at St Mary's. Then at school this othering intensified in the experience of what felt like surveillance and witnessing another sibling being continually bullied by peers, but also by some of the teachers, arguably through what one may relate to as microaggressive behaviours (Pierce, 1989; Sue *et al.,* 2007; Gonzales *et al.,* 2015).

Moreover, I also othered my siblings and then myself. In relation to the latter this other remained hidden from view, only now being united through a critical cognitive process, that has enabled me to deconstruct and reconstruct a new perspective and orientation (Mezirow, 2000). Ironically, I was then 'othered' in the medical discourse. This would appear to have been a deeply ingrained insidious process. My medical narrative was the vehicle that transported the

'pseudo-medicalised identity' into my adulthood, whose presence lingers and would seem to have a continued influence within the therapeutic encounter.

Arguably, through the doing of autoethnography my dissimilitude has been assimilated, the synthesis offering the potential for greater authenticity in practice. However, this does not mean I have surpassed any possibility of further emotional distress. I, like everyone else, am susceptible to life and all that it throws forth. But as I situate within the contemporary context with this new take on my reality, where the need may necessitate the seeking of professional help, I am positioned with greater autonomy. It has taken many years to personally reach a point in life where I am able to reflect on this deeply personal experience to view more objectively and politically. I would suggest this places me in a position whereby I not only have the lived experience, but also the professional knowledge, this union providing a generative uniting through this inquiry of the 'specialist' and the 'other'. For this reason it would appear there has been symmetry and synergy to harness such change.

Finally, from my reading on the history of this genre it is a methodology that has been the subject of its own othering within research communities. From the outset of taking the first tentative steps towards autoethnography, I was concerned that many viewed the approach with a degree of cynicism, even dismissing it as 'non-scholarly' inquiry (Delamont, 2009; 2012). However, this

ambivalence centred on the need to conform to a more 'traditional qualitative study' only served to fuel my interest and a conviction to walk its path.

5.2 Disconnection

"*To cut off from something*" which in this case was a self that was too shameful to speak about (Cambridge Dictionary, 2017).

The childhood distress became an impasse in my learning as if time had stopped. Any liminal phases of development were thwarted, stilted and blocked until I had moved to a stage in life where the chaos had settled and the fog that lingered was starting to clear, revealing a path that would direct me through education to the investiture of a new ontology (Land, Rattray and Vivian, 2014). Giddens (1991, p.9) introduces the notion of "*existential isolation*", which he explains as relating to an individual devoid of what he refers to as "*moral resources*", ones that are important for a fulfilling life. He suggests that both guilt and shame manifest at the same time, but shame is public. The other side of shame is to be self-confident and "*transcending of shame leads to secure self-identity*" (Gidden, 1991 p.67). Through becoming more reflective of my situation and sharing the stories, these two concepts can be in a dynamic interplay towards change (Freire, 1972). To reconnect with the disconnected resulting in greater empathy towards self (Karp, 1997), and providing the opportunity to breathe (Frank, 2010).

5.3 Bifurcation

" the act of dividing something into two parts" "disunite" "split" "divide" (Cambridge Dictionary, 2017)

The circumstances of bifurcation conveyed within the stories '*Growing Shame'*, reveal there were two very separate realities or identities of self. The joining of this "*biographical discontinuity*" (Goffman, 1990a p.99) has been possible through this inquiry, to restore an up to date biography. Goffman referred to these ideas in relation to other people's knowledge of an individual. An interesting paradox to reflect on here is that I refer to the significance of historical continuity and the temporal nature of reality. However, as has been discussed by those such as Giddens (1991), with illness comes a discontinuity. Hence, the study has attempted to reflect on moments of this discontinuity and a reintegration of one's life. For me personally it has enabled a restoration of biographical continuity of self, yet I am still the same person with the same history.

In line with the process of bifurcation what is needed to move beyond is an assimilation of the self and other in order to transcend a stigmatised identity, to be fully authentic in both my personal and professional spheres. Autoethnography as a method allows for an awareness of this "*dual consciousness*" and through this process I have navigated my way through a self- and societal-enforced boundary. (Reed-Danahay, 1997, p.4).

5.4 Assimilation

"*the process of becoming a part" "joining" "band together*" (Cambridge Dictionary, 2017).

This has been a transformative doctoral learning journey, one allowing for the acquisition of new knowledge, but also as Mezirow (2000) would assert: it has been a conduit for the reintegration of identities to enable greater competence and self-confidence in practice. The reflexive dyadic processes have facilitated an understanding of equity between self as researcher and the researched (Burr, 1995), and a sense of movement within a 'dualistic' reality. Further to this, when one arrives at an awareness of the mechanisms of structural oppression, there is opportunity for transformation, deeper authenticity and a new understanding of the forces that serve to dominate (Cannon, 2016).

As previously implied, autoethnography has served to have an emancipatory function. This 'freeing' process underpins the values inherent within critical pedagogy. Whereas Freire (1972) would cite revolution, I would argue what is required is a 'revolution of consciousness'. For me this has occurred through education, and reaching a pivotal moment on my doctoral rite of passage (Van Gennep, 1960). I have finally been able to make my own interpretation which I may present in practice rather than listening to the experience of others as a silent observer.

The unfolding elements of this inquiry became a 'living exploration' of the perspective transformative process. This is arguably a powerful medium for 'concientization' (Freire, 1972) of being within a multi-faceted context shaped by culture, temporality and structural power dynamics that have interacted and continue to interact. To achieve this reality and praxis for the emergence of a hidden identity released from many years of psychic containment "*when a synthesis is struck, when the two ends of the tension are resolved, they are not resolved in the same terms that led to the tension in the first place. Always something quite new and unexpected emerges"* (Daloz, 2012 p.141).

5.5 Transformation

"a complete change in appearance or character of something or someone, especially for improvement" (Cambridge Dictionary, 2017)

The meaning of a stigmatised identity and its importance within a dialogical learning space has changed profoundly *"because (I) we have left home, seen it from afar, and been transformed by that vision". "You can't go home again – or rather, the home to which you return is not the one you left"* (Daloz, 2012 p.27). He further asserts that for this transition to occur, we have to "get lost". He, along with seminal autoethnographical writers, believe that middle age is the time when we may begin to ask fundamental questions on the meanings attached to our lives, a process that involved a position from which to accept, reject and construe our understanding and awareness towards power structures and live with greater veracity (Daloz, 2012).

Daloz (2012 p.255) discusses the capacity in many for a quality of "*shared humanity*". In order to have this quality, there is need for a developed sense of empathy. This often is instilled and nurtured by personal experience of adversity and this knowledge engenders a sense of receptiveness to this in others. It is easy to see that a deeply entrenched stigmatised identity may close someone off to the plight of others. Or that stigmatising attitudes held by the public become a block that is very difficult to move beyond. This may be the case for many, and it is this process that perhaps perpetuates a negative stance or an oppressive reality that halts movement.

So now I turn my attention to the second question and ask myself - ***how do these stories connect to my doctoral journey, professional practice, and the underpinning socio-cultural and ideological discourse*****?**

It is important to note that question 1 sort of melds into question 2 as the stories' themes are deeply intertwined with the doctoral journey facilitating my generative movement back and forth to a new position. Therefore, it is difficult to have a neatly demarcated distinction between the two. The findings link to my doctoral journey, practice and the literature reviewed in Chapter Two. The transformation is most prominent as it is the end point, but also arguably a starting point.

Freire (1972; 2013) and Daloz (2012) firmly believed in the power of education for transformative purposes, such that they have the capability to harness and introduce potential catalysts for social change. This relates here to a new way

of thinking and a conduit through which to move beyond a stigmatised identity and negative associations towards mental health. As an educator committed to anti-stigma pedagogy Freire's (1972) theoretical insights excite, as through the learning of lived experience within a dialogical learning space small steps may be taken towards changing deeply entrenched negative internalised individual and collective attitudes. Learning that promotes dialogical opportunities is fundamental to new knowledge and change. In order for this to occur it is important for me as the subject of the research to have first examined the transformative process in order to not perpetuate the oppressive structural forces.

"*the act of new naming reifies the unseen and draws us upward; at once it adds a new rung to the ladder and calls us to climb. From "I am right" to "you are right" to "we both have rights," the idea of justice allows us to break out of the trap*" (Daloz, 2012 p.141).

It has been suggested that it is important to "*greet the self as teacher, before the greeting can be extended to students or colleagues or patients*" (Stolder *et al*., 2007 p.265). Mindful of the above insights, the autoethnography has allowed me to examine what I do and how I do what I do. In addition, do I and my lived experience and self-identity "inform or deform" my relationships with those situated within my practice – students, colleagues and the knowledge base I strive to impart (Palmer, 2007b)? Thus, the process of self inquiry is central to understanding the above.

Within the context of health pedagogy, as suggested above suffering, and in this case the lived experience of stigma connected to mental health, may be understood through the development of empathy. Indeed, having empathy instils a human dimension and awareness of suffering (Robinson, Kendrick and Brown, 2003). Studies such as Matteo (2013), Bizub and Davidson (2011), and Muzyk *et al.*, (2017) allowed space for reflection on attitudes and the development of empathy.

Therefore, the creation of conditions for an empathic learning space that allows and encourages open discussion of human emotion is deemed as a necessary condition for anti-stigma teaching (O'Reilly, Bell and Chen, 2012; Bryne, 2013; Matteo, 2013; Friedrich *et al.*, 2013; Bharathy, Foo and Russell 2016; Muzyk *et al.*, 2017), a space for the sharing of experience and for the promotion of a togetherness (Zahvi, 2014). My autoethnography as a site of research has replicated this process not only at meta-cognitive level, but also making connections in the wider socio-cultural and political context. As a research product but also as a medium for teaching it may provide therapeutic benefits through the stories in order to reframe attitudes and improve the way we think (Crawford, Brown and Crawford, 2004).

In line with Hauerwas (1986, in Robinson, Kendrick and Brown, 2003 p.62) suffering really can only be fully comprehended through reflecting on "*particular stories and experiences*" and by having the opportunity for this to potentially enable more 'positive' attitudes to surface. But also to consider how

knowledge confers power and biomedicine is arguably positioned as a hegemonic force to do this (Zeeman, Aranda and Grant, 2014; Sarroub and Quadros, 2015). Paradoxically, the literature revealed pedagogy framed within a biomedical perspective was not conducive to initiating change (Boucher *et al.,* 2014). Similarly, it is suggested the curriculum also has potential to be oppressive and harmful (Grant, 2016a). Therefore, it would seem reasonable to suggest the importance of promoting opportunities for a more holistic model within the teaching and learning context (Poreddi *et al.,* 2015), along with creating opportunities for 'criticality' throughout (Grant, 2015; Grant, 2016a; Smith and Grant, 2016), to enable work on self-awareness through reflective learning in order to affect the way mental illness is perceived but also how it is felt (Freire, 1972; Mezirow, 2000; Bolton, 2010). Therefore, learning may well cause much discomfort (Boud and Falchikov, 2007), but should not be shied away from.

Furthermore, the nurture of conditions to promote empathic resonance is important for a conducive pedagogical environment, such that enables listening, reflection and empathy. The knowledge produced from this inquiry will strive to challenge assumptions, practices and power dynamics that may exist and this is more likely to develop *"from dissonance between experience and other knowledge claims and may be individual or shared by a group*" (Scott *et al*, in Lester, 2012 p.269). Arguably from my position as an educator, I offer an embodied 'link' that may confer greater resonance than a more theoretically positioned one (Palmer, 1993). Bryne *et al*., (2013) highlighted the opportunities education has for increasing empathy through self-awareness of

our pre-conceived ideas and move to a new frame of reference. Teaching spaces that create the conditions for 'empathic resonance' are essential for feelings to be bought into the learning. This has a synergy with autoethnography and its utility in teaching is that it is a "*felt-text*" (Spry, 2001).

Palmer (2007a) argues without feelings being acknowledged there is a risk that other truths will not be revealed be these intellectual or emotional. This involves the creation of conditions that allow for a tension between the consideration of the concept of stigma as well as acknowledging that learners need to explore the issues with a level of openness. In order for this balance to be created it is vital that the teacher is able to be accessible and authentic with their own feelings and identity (Palmer, 2007a). For me to be congruent in my professional identity, I needed to feel I could be open with my own lived experience, something that I had long ignored and buried, despite it being a central element within my pedagogical practice.

The disorientating dilemma has led to an epistemic evaluation of my own pre-conceived ideas of self, enabling me to reflexively move through these towards having a greater empathy of self. The undertaking of an inquiry of self has changed my own attitudes. Matteo (2013) talks of a 'social development process' which may be gleaned from the stages of the inquiry and the critical pedagogic influences. The students in the aforementioned study discussed peers who had been segregated due to mental illness and this was only in

2013. I present my stories of segregation and how these were continuous through different temporal moments and influenced by historicity.

According to Mezirow (1997 p.5) transformative learning enables individuals to be more independent in their cognitions and growth. *"..a defining condition of being human is that we have to understand the meaning of our experience*". It may then be conferred education is a powerful medium that can provide scope for learners to become critical thinkers, in this case the thesis attempts to capture the essence of this process, the emancipatory effects this may have to move to a new awareness. Therefore, I am recommending in line with others the potential for the 'stories of lived experience'. In line with a critical pedagogical approach, it is my role to raise awareness of and help my students be critical of their and others' attitudes towards mental health. This process is essential in the 'reframing' of potential negative attitudes and providing opportunity for an active engagement in the discourse.

This autoethnography as a process and product has been the vehicle for my perspective transformation and a change in my '*frame of reference*' to one that has greater authenticity (Mezirow, 1991; 1996; 1997). Our frames of reference, or view of reality, are deeply influenced by our cultural context as well as our peers, in particular our caregivers from a young age. *"a frame of reference encompasses cognitive, conative, and emotional components, and is composed of two dimensions: habits of mind and a point of view*" (Mezirow, 1997 p.5). Stigmatising attitudes are a habit of mind informed by our experience, values

and feelings, often acquired in childhood, for example from teachers, parents and peers (Mezirow, 2000). The way we change these assumptions is through a critically reflective approach.

The learning should not be offered as a token, rather it requires an ongoing approach with students (Roberts *et al.,* 2008). The vision of the anti-stigma teaching and learning, along with this research inquiry, holds on to the importance of the condition of reciprocity in dialogue between those involved with what Entwistle (1979, in Gitlin, Siegal and Boru, 1993 p.204) refers to as a underpinning philosophy that is inherently political and instils a desire to take action for social change. Through dialogue this may become a possibility in the shared teaching space to move to a more sustainable and positive reframing of our capacity to discuss and be open about emotional distress.

5.6 Study Limitations

Turning to consideration of the study limitations; at the outset, what became notably obvious was a strong critique from within research communities of the 'rigour' of autoethnography. It would appear many consider this approach with caution and as such subjected it to rather harsh criticism (Holt, 2003). It has been referred to as a 'fringe' methodology, one rooted in narcissism (Coffey, 1999). Similarly, due to the emphasis on self as the site of the research, some view this level of subjectivity as lacking the rigour of more objective approaches to investigation (Delamont, 2009; 2012). An example of such attitudes is

articulated in an evocative account of the personal trials and tribulations of doing an autoethnography which included issues such as navigating ethics and issues of trustworthiness (Forber-Pratt, 2015).

The undertaking of this thesis and its particular methodological orientation has allowed for deep analytical reflexivity which some in the research world have described as 'navel gazing' (Delamont, 2007). However, I would argue that drawing on my lived experience of the phenomenon of stigma and capturing a transition through a stigmatised identity has allowed for rich textural data. Indeed, such experience is central for both research and practice (Carpenter, 2006). Furthermore, the purpose is relevant and contemporary. It has been exciting to conduct an inquiry that may be viewed as one that challenges the more distant and objective genres that are more often encouraged within academia (Behar, 1996).

Additionally, the use of self-observation and the process of the observer being observed, in contrast to observing others to produce a second-hand analysis, may arguably serve to enhance trustworthiness (Rodriguez and Ryave, 2002). It is fair to say that this thesis does not attempt to provide an objective analysis of the data (situated within the stories presented). The approach to the sense-making of the stories situates the self and therefore subjectivity at the heart of the inquiry. The use of memory that is influenced by my own feelings, enables me to make links to my own stigmatised identity and stigma within the wider society and within the

learning space to collectively consider "*the ways and means of achieving and magnifying (that) well-being*" (Damasio, 2012 p. 297).

Further to this, a single story could be viewed as a limitation, particularly from within more conventional research communities. However, in line with the philosophical underpinning the sharing of this narrative will provide conditions for verisimilitude, the reader left to make their own sense of the stories. I would argue the very strength of such a method requiring this high degree of subjectivity, one described as 'leaving the blood in' (Moriarty 2013) allows for the development of narrative which may then be available for the audience, to create conditions for resonance and meaning. The stories are "*subjectifiers*" of mental health (Frank, 2006 p.421).

Of course, when considering 'narrative privilege' there are arguably limitations. These are centred on my experience and thus not the stories of others which may reveal further insights into the experience of stigma. Conversely, there is possibility for multiple truths. My interpretation of reality is informed by others' notion of this, with capability for refraction. Having opportunity to analyse from multiple perspectives and stimulate reflexivity encapsulated the ideas on crystallisation discussed in Chapter Three (Richardson 1994; Ellingson, 2009). Therefore, for me this is a strength, offering opportunity to consider reality from different perspectives through dialogue to move to a new position or "*a metanoia*" (Wright, 2006 p.61).

There are two further possible disadvantageous issues that are worth considering. The first relates to the "*emotional climate*" in which one positions practice-orientated research. As has been suggested a "*toxic climate*" may not be easily resolved through a lone study such as this. On the contrary it may arguably be made more controversial. Secondly, as the anticipated outcome is to share the stories in my pedagogical role, then attention is required to the emotional terrain and the need to remain open to the possibility that it may not be a positive experience for all (Dadds 2008, p.287). Wall (2008 p.50) discusses 'voyeurism' and aligns with Ellis and Bochner (2000, p.749), "*personal stories indulge our culture's perverse curiosity about the private, peeking in on damaged selves*". The personal and in this case the sensitive nature of the topic may cause discomfort. Therefore, learner safety needs to be considered and students made aware of the possibility for discomfort (Cousin, 2008). From a learning perspective a further caution is for teachers to be aware of 'mimicry' rather than mastery over the issues (Cousin, 2006). Furthermore, those that have attempted this method previously have cited that it is potentially a very challenging one to undertake (Wall, 2008). For this reason attention to self-care throughout was implemented.

5.7 Summary

This chapter has considered the findings in relation to the research question, offering some further theoretical underpinnings. The doctoral journey bought me to autoethnography, indeed a gift from which I was able to share a personal stigma story and consider in-depth the nature of

my own stigmatising attitudes. As a result the learning has enabled growth and demonstrates the power of reflective or deep learning. The stories may be offered in the form of educational tools within my practice with potential to address the negativity that continues to surround mental illness. The proceeding chapter will consider the contributions to knowledge and recommendations for practice and research.

Chapter Six: Conclusions

Herewith, I offer a more holistic overview of some of the most salient issues revealed, along with the studies original knowledge, practitioner and research focussed contributions. Indeed, within this chapter I provide a learning framework and recommendations to add an analytical dimension. These recommendations have been made in line with my research questions and link to the ways in which my stories may be shared in different settings. Whilst not strictly in concordance with the personal subjective elements of this autoethnography they are presented in a way that makes connection to the wider sphere, to add an academic dimension (Tedlock, 2015). Thus allowing a synergistic union to fulfil my doctoral learning outcomes, and provide a platform for the evocative stories to connect to the broader context. The stories may then be used for students to do their own sense-making. Finally, I present some of the challenges of undertaking an inquiry of self.

6.1 Original Contributions to Academic and Professional Knowledge

The initial epistemological offering is the 'stigma stories', and the potential capacity contained within these personal narratives to bestow a transformative learning exposure. It is anticipated that the knowledge and interpretations gained from the stories will be beneficial to considering the actuality and profound impact of stigma, through the dialogical learning potential, as a stimulus for imagination and acknowledgment (Charon, 2008).

Furthermore, the stories provide a conduit through which the reader is able to step within someone else's lived reality of stigma, in order to forge their own understandings. This will promote "*the circularity of reflective practice*" to unite the individual to the collective (Crawford *et al.,* 2015 p.51). The inquiry presents personal 'truths', ones that this investigation has striven to make sense of. The insights are framed in Guba and Lincoln's (1989) criteria for trustworthiness. The motive not to claim any final words, rather, create a medium in which to engage in a 'generative process' of storytelling to initiate a change. Through autoethnography other writers have captured the reality of living with a stigmatised identity (Harrington, 2014; Grant, 2014b; Grant and Leigh-Phippard, 2014). However, no one person will experience their reality in the same way as another. Mindful of this, there is an authenticity that may resonate with the reader, but may not necessarily be replicable. Instead providing a catalytic opportunity for sense-making rather than one that attempts to dictate the final last word (Moriarty, 2013). Certainly, through a resonance of shared experience there is capacity for a connection (Trahar, 2009).

Undeniably, the exposing of a self that hid secrecy, shame and guilt and gaining an awareness of the processes that helped to create my pseudo-medicalised identity has been liberating. There is an emphasis within the contemporary research arena, on *"the role of practitioners in constructing and reinterpreting knowledge in work settings through reflection, observation and practical experimentation"* (Lester, 2012 p.268). My disorientating dilemma involved a high degree of reflection and

observation which at times rendered a painful self-consciousness and sociological awareness (Wright Mills, 2000). I have taken introductory steps in experimentation with praxis and dissemination (Appendix 11 and 12) but envisage this will be more active in my future work.

An initial recommendation; one I will consider further development on, relates to the concept of a *pseudo-medicalised identity* and ways it may be employed in my teaching and learning at both undergraduate and postgraduate level. Moreover, this could be favourable within a continuing professional development (CPD) context in the multi-disciplinary healthcare arena as a reflective learning mechanism for practitioners to consider. This may be of particular importance for mental health staff such as psychiatrists, nurses and social workers to enable a shared space for dialogue and empathic learning. The literature that ignited this study, suggests that negative attitudes quickly returned following anti-stigma pedagogy, particularly when staff were situated back in practice. (Economou *et al.*, 2012; Altindag *et al.*, 2006; Friedrich *et al.*, 2013).

As revealed here, I was the girl with an 'intractable problem', a rather negative opinion from the outset that would appear the medics were unable to detach their thinking from. Terminology such as "intractable" which may be defined as "*not easily controlled, stubborn obstinate or when relating to medicine hard to treat or cure*" (Cambridge Dictionary, 2017). In connection with mental health this reflects the discourse of the 1980's, but also echoes the negative associations that are still harboured.

Conveyed within such terminology is a lack of hope, a pessimistic view of an individual's potential for recovery. Of course, it may have been an appropriate term to use when all had been attempted to no avail. However, the term was used from the outset of my first steps to seek support in teenage years and this I would suggest was the key in the evolution of a pseudo-medicalised identity. Similarly, when considering the stigma definition of "social construct" or "negative stereotype" (Lester and Glasby, 2010) it may be seen from the evidence doctors are at risk of inadvertently doing this.

6.1.1 Anti- Stigma Learning Cycle

Furthermore, through the process of the research, a pattern was identified within the themes that may be mirrored within a ***learning cycle*** or stages through which I moved through the stigmatised identity (Diagram 6.1). Interestingly, what has been revealed is something distinctive to stigma and is hoped may provide a useful tool within my pedagogical practice. The scope of this may be extended to include inter-professional learning opportunities on other programmes of study. Moreover, connected to the literature review, my own attitudes shifted through the doing of autoethnography. Its power to provide an epistemological renewal from an identity I had become firmly embedded in. It allowed space for analysis and an attempt to "*have it*" rather than "*be had*" by it (Kegan, 1994 in Mezirow, 2000 p.25). The perspective transformative process occurred and I now have greater empathy for the other self and this joining is possible through knowledge (Sartre, 1993).

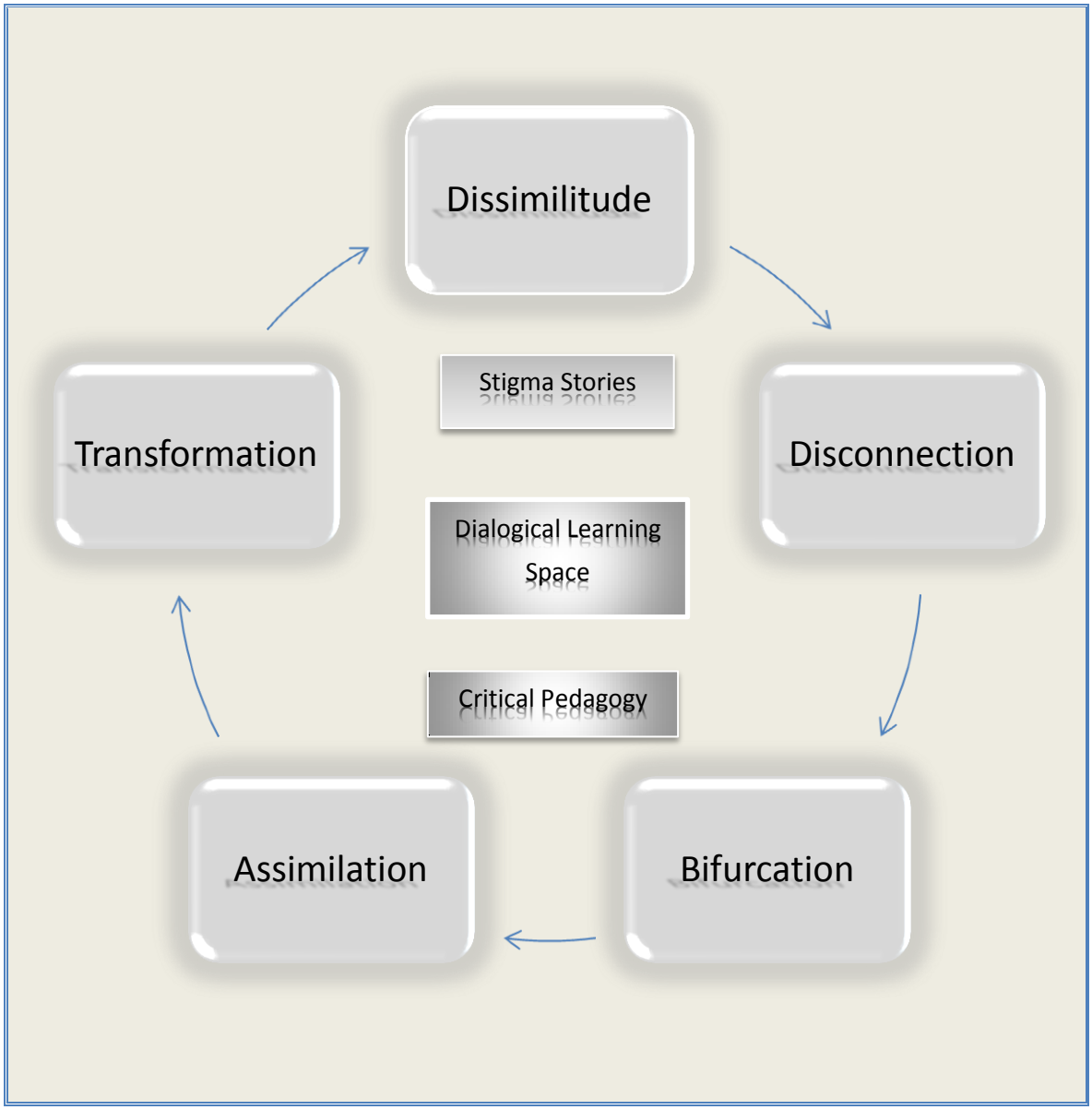


Diagram 6.1 Anti-Stigma Learning Cycle

It has also been acknowledged by scholars that autoethnography resonates with the anthropological concept of 'rite of passage' (van Gennep, 1960) for its liminal qualities. The 'in-between' space a place for theory, practice analysis and action. (Jones, 2005 p.784). More recently, the idea of 'threshold concepts' have been considered within the educational context (Cousin, 2006). One idea is their utility in providing a specific focus on important conceptual issues, in this case a stigmatised identity. Discussion on stigma is a sensitive and emotive topic and the concepts within the learning cycle provide transformative stages or 'jewels within the curriculum', which may lead to

richer understanding (Land, Cousin, Meyer and Davies, 2005). The themes acting as conceptual gems infused with our values, ones shaped by socio-cultural and historical factors, to be offered for dialogical exchange. Within my anti-stigma practice, time may be devoted to consider these gems and within each provide a 'liminal space' to examine on a 'meta cognitive' level the critical events at play in order for learners to discuss and reflect on these to drive a shift in ontology (Land, Rattray and Vivian, 2014).

The above point having saliency as the literature reviewed revealed student attitudes, quickly reverted back to more negative ways of thinking. It has been suggested they offer a way of working with 'troublesome' or 'nettlesome' knowledge' to evoke a fresh way of thinking (Cousin, 2006; Meyer and Land, 2006; Sibbett and Thompson, 2008). Furthermore, the stages of the learning may be harnessed through the stories to act as further catalysts for dialogue that challenges pre-conceived ideas, presents new ways of thinking and enables a dynamic interplay of ideas (Freire, 1972; Mezirow, 1996). Such that may contribute a 'small generative link' (Perkins, 2008) in order to contemplate a lived reality of the phenomenon.

6.1.2 Right Stigma

What's more, moving through the distinct themes enabled the writing of my story or the 'righting' of my story. What I mean here is by situating self as the site for an inquiry, I have through a systematic and deeply analytical process enabled a sense of re-orientation. The 'righting' is a term to signify correcting

something that somehow intuitively did not feel right. This was certainly the perception deeply ingrained within my psyche from a very early age. By the 'righting' of my story I am able to be more fully authentic in practice. However, this is only one element within the complex web of forces that continue to perpetuate stigma. This 'righting' is required as indicated above on many levels, not least in the education of medical and health care providers. It is anticipated that this story will contribute to a growing body of narratives that draw on the contribution of the lived experience of stigma evolving from emotional distress within the teaching context (Deegan, 1997; Grant, 2006; Grant, 2011; Grant, Biley and Walker 2011; Grant, 2011; Short, 2010; Bizub and Davidson, 2011; Glover, 2012; Matteo, 2013; O'Reilly, Bell and Chen, 2012; Bryne *et al*., 2013).

In addition to this, my stigma counter narrative has served to act as a "*progressive qualitative device*", (Grant and Leigh-Phippard, 2014 p. 100) to ignite in a diametrical dance of resistance against the dominant discourse. Moreover, to interact within the thesis in a generative way to move towards assimilation and integration, to harness this tension and convey a sense of ongoing dynamism for lifelong learning and growth. *RIGHT STIGMA CAPABILITIES* may be offered within a learning environment to generate critical reflective thinking and hopefully self-awareness which is an important quality for a reflective practitioner in the 21st century. To cultivate the ongoing glimmers of hope for a more empathically driven workforce that ignites these competencies, along with being open and facilitating empowering relationships.

Rather than fall into the trap of succumbing to negative discourse within the therapeutic context, RIGHT STIGMA may facilitate a bridge to offer health care workers a path upon which to consider their practice in relation to the professional/service user encounter. To favour the need to become aware of the language that is used and the impact of such on the recipient (Brown, Crawford and Hicks 2003). In line with generative thinking this may stir awareness of critical self- reflexivity in order to become more cognizant of how attitudes may affect someone in the midst of emotional distress, where vulnerability and sensitivity are heightened to negativity. The fear of how one may be or is perceived may be a block in moving forward and serve to fuel a possible stagnant environment. In line with critical pedagogy the consideration of each of these capabilities may foster concientization to praxis (Freire 1972).

Arguably, there is little cost associated with the above contributions, which has to be a consideration when training budgets are constrained and services being cut. It involves cultivating a re-orientation of mind-set or a mindfulness of personal requirements for effective conduct, such that promotes dignity to remove barriers that prevent help-seeking and improve client care (Bannatyne and Stapleton, 2015). Attempts such as DoH (2004) 'Ten Shared Essential Capabilities' have been and continue to be a powerful values learning framework. However, if negative attitudes and perceptions remain unconsciously harboured within the workforce then implementing these is undeniably challenging. I would suggest the change in thinking around stigma has to be the first and foremost consideration. Stigma as a phenomenon and invisible force holds back the development of services in the direction of a new

culture that embraces difference and diversity, which acknowledges the fragility of humanness and the capacity to make a difference through individual and collective agency. As I have discussed within this inquiry both external and internal stigma insidiously interact and feed off one another. Therefore, any attempt to 'right' is advantageous for the individual and society.

RIGHT Stigma Capabilities

***R**espect* – in relation to the therapeutic encounter, the manifestation of this personal quality is central for cultivating an appreciative environment. One that allows the self- esteem of the service user to remain intact.

***I**ndividual* – within the health and social care context there has been much written on the practice of person – centred approaches. Of paramount significance in the face of stigma is to 'see' the individual and not the 'label' or what may have been presented in the discourse. Importantly, there is someone behind the distress. Getting to know the individual behind the emotion is conducive to righting.

***G**enuine* – to be positive, and natural to allow space for a deeper authenticity and cultivate a recovery orientated environment.

***H**onest* – to be truthful and straightforward. To practice a non-judgemental approach.

***T**rustworthiness* – service users need to feel this for any therapeutic alliance to be favourable to promoting recovery. A quality to enable openness and discussion of feelings without a fear of judgment or stigmatisation. Also as has been suggested by Goffman (1987) a trust that professionals will work in a way to ensure ethical values are maintained.

I have since reflected on how those responsible for my care would feel if they were to read my thesis. Ethically speaking, I have only included stuff that I would be happy for them to read.

"What would they think, would they get defensive, angered, perhaps even eject me from the consultation room?"

I imagine a considered response to such a reaction, rather than one triggered by emotion –

"it is important to hear my interpretation"!

"you know the doctor is not always 'RIGHT', and presents as only one side of the encounter".

"it has to be realised the 'patient' is often the 'expert' of their health".

"a dyadic with a potential to 'RIGHT', with us both on equal footing could be highly synergistic".

Through a dyadic discussion comes a possibility to consider pre-conceived ideas. The 'righting' comes from the partnership, the tension within this is potentially transformational. So it is important to emphasise that these are my attempts to provide further discussion of the lived experience of a stigmatised identity and how these connect to my professional practice and the wider socio-cultural and political context. The above tools

contribute to the range of educational approaches deemed necessary to enable students to consider the topic of mental health and provide opportunity to examine existing attitudes and perceptions (Yamaguchi, Mino and Uddin, 2011). To do your own 'righting' whether healthcare professional, student, service user or just interested party.

6.2 Further Contributions to Education and Training

6.2.1Pre-conceived Ideas

The Royal College of Psychiatrists (2009) position statement places significant emphasis on the role members play as key drivers for change. Therefore, education of this powerful group of professionals is considered a valuable catalyst for service innovation. Power issues have been highlighted within this thesis, as well as indicated in previous studies (Foucault, 1988; Smith, 1990; Bourdieu and Wacquant, 1992; Brown, Crawford and Hicks, 2003; Grant, 2015a; Brown, 2015). It would appear that influential groups tend to hold greater stigmatising attitudes that are more resistant to address (Knapp et al., 2007). From a critical feminist perspective, the practice and knowledge of biomedicine contains embedded assumptions that for mental health have their roots in 19th century psychiatric discourse (Showalter, 1987; Smith, 1990; Appignanesi, 2009). This thesis has enabled a self-verbalisation of some of the issues that are attached to what would appear at first sight the stigmatising attitudes, or pre-conceived ideas held by the medics responsible for my care. Research suggests these negative attitudes develop early in a doctor's career and risk resulting in a lack of empathy

(Bannatyne and Stapleton, 2015). This may then lead to both overt and subtle experiences of 'microaggression', that arguably the "perpetrators", are not aware of the distress that such behaviour may inflict (Pierce, 1989; Sue *et al.,* 2007; Gonzales *et al.,* 2015).

Mindful of the above, a further recommendation is that Medical Training at both undergraduate and graduate level should include anti-stigma pedagogy within the syllabus. In addition a training package may developed for medical practitioners in the form of CPD. This will allow individuals to actively discuss issues relating to discrimination, prejudice, and bias. This supports previous studies where issues of stigma and discrimination have played a significant focus to good effect (Altindag *et al.*, 2006; Bizub and Davidson, 2011; Mann and Himelein, 2008; O'Reilly, Bell and Chen, 2012; Bannatyne and Stapleton, 2015; Poreddi *et al.*, 2015; Bharathy, Foo and Russell, 2016). One particular area of importance is the medic's role in the therapeutic consultation, which includes the language that is used and how the meeting is documented and then conveyed to the service user. As highlighted earlier the discourse used may be powerful in shaping perceptions, unconscious bias and the therapeutic outcomes. This alliance is central to positive outcomes (Bryne *et al.,* 2013).

As suggested by Sibbett and Thompson (2008 p.237) "*such professional training may engender fidelity and foster the development of practitioners who have greater capacities to be more authentic, develop constructive relationships and have a deeper understanding of the troublesome*

knowledge, threshold concepts and liminal areas". Also to present models of education that do not totally rely on knowledge underpinned by a bio-medical approach (Poreddi *et al.*, 2015). Rather one that incorporates bio-psycho- social, and spiritual elements with phenomenological episteme's weaved within and throughout. To capture the complexities of a reality and looks at all dimensions of personhood, to avoid creating "*schisms*" of reductive thinking (Powell, 2007 p.164). To use the personal stigma stories as a way of moving to a human paradigm in psychiatry (Grant, 2015a).

6.2.2 Temporal Considerations

A further recommendation is the importance of creating conditions that may then make way for sustainable pedagogy for positive attitudinal change. To educate in order to tackle structural discrimination and promote a better understanding of roles (Royal College of Psychiatrists, 2009). As has been previously suggested, ongoing efforts are required rather than single tokenistic events. These one off attempts are not deemed effective and as indicated within the literature review do not have a lasting impact on opinions (Roberts, Wiskin and Rolfe, 2008). Within education this is important within a multi-disciplinary context and should involve learning for continuing professional development at different stages of the practice life-course.

At a time when mental health care is woefully underfunded and staff are overstretched and stressed never has there been a more important time to

consider some of the above issues. Why? Well as was elucidated from my literature review, negative attitudes may quickly creep in resulting in staff potentially becoming closed off, losing the ability to fully connect with others. The literature suggested some of the negative attitudes harboured by staff are as a result of burn-out (Economou, 2012). This phenomenon if left unchecked may lead to mental distress. Therefore, it is important for organisations to provide support to ensure that workers remain open and person- centred.

Research has identified high levels of mental distress among healthcare workers, for which adequate support is not available (Hall *et al.*, 2016). This is not conducive when providing support to others (Moll, 2014), and may impact on an individual's self-worth. Turner (2012) considered the concept of self-worth in relation to nursing and it has also been acknowledged negative staff attitudes are a concern among health professionals (Horsefall, Cleary and Hunt, 2010). For the above reasons it is recommended supervision and mentoring are important areas for further practice development. The learning tools arising from this inquiry support the calls from the literature for learning from an academic with the lived experience and importantly for me one who has considered and moved through their own negative attitudes.

If statistics are to be believed it is predicted that depression will rank as the leading cause of disease by the World Health Organisation over the next couple of decades (WHO, 2014). Doctor's themselves have been found to be prone to such concerns along with high incidences of alcohol misuse.

Interestingly, research reveals they are fearful of disclosing such in case it has a negative impact on their professional identity. Seventy three percent of doctors would not seek professional help for mental health issues for fear of the impact this may have on their career or professional reputation and also due to the perceived stigma attached to such (Hassan *et al*., 2009).

Staff should not shy away from discussing their own emotional wellbeing for fear of discrimination. There are drivers in place that support this such as The Equality Act (2010). However, the literature upholds the fact that staff avoid doing so, and in instances where they have, report being demoted or losing their job. Additionally, for those who have been open, there are stories of then not being able to find employment or invited to interviews to be in a position where they may have a chance of gaining work (Gonzales *et al*., 2015).

Mindful of the above, there are opportunities in line with legislation to ensure that all organisations in health and social care have support mechanisms in place that take a proactive approach to staff wellbeing (DoH, 2005; Department for Work and Pensions (DWP), 2013). Indeed, attention to the above is a crucial factor to how well practitioners respond both empathically and compassionately (Crawford *et al.,* 2014). Another point worthy of note is this should be embedded within the curriculum of professional programmes prior to the world of work (McAllister and McKinnon, 2008).

As highlighted, engagement with educational activity may provide a safe space for self-disclosure of personal experience of mental ill-health (Matteo, 2013). I too hid my fears for many years and now wish that I had taken action much sooner. What held me back? STIGMA! My own negativity to self that was a product of the discourse that has insidiously shaped my own perceptions and those of the wider collective. These powerful often hidden forces are what Foucault (1991) referred to as the 'micropolitics' of power. This study has added to the literature through enabling me to understand my own internalised attitudes and the impact these have had adding to the other studies that have attempted to examine the nature of stigmatising attitudes (Madden, Aguiniga and Zellmann, 2014; Szeto, Luong and Dobson, 2013).

The learning opportunity whilst initially considered in the context of public health and social care may translate to a variety of multi-disciplinary contexts within both primary and secondary care to work towards public and policy initiatives (Time to Change, 2008; 2009; Department of Health, 2004; 2011; 2012). Within critical pedagogy it is important to begin learning with a topic that enables the learner to self-examine their own ideas, attitudes and perceptions towards the subject to act as a catalyst for perspective change (Matteo, 2013; O'Reilly, Bell and Chen, 2012; Bryne *et al.*, 2013; Friedrich *et al.*, 2013; Clement *et al.*, 2012).

The Alma- Ata vision of health for all by the year 2000, or in this case mental health, is still a long way off. In difficult economic times

population health and wellbeing is affected (WHO, 2011). Only recently the government is looking to increase staff within mental health service provision due to the rising incidence of mental health issues (NHS, 2017). This is all laudable if it comes to fruition. Pledges have been made by previous governments and within the historiography of mental illness one can see that stigma has always been an impeding factor within the changing ideas towards mental health (Porter, 1987; 1993; 1999; 2003).

Therefore, until attitudes and perceptions of emotional distress are openly discussed and supported then change may be a long time coming. As Freire (1972) would assert in line with the notion of 'generative themes' within and throughout different epochs, ideas and concepts are considered and debated until a movement towards social change is achieved. The time is 'RIGHT' to put the topic of stigma at the forefront of services and in line with what the research strongly indicates this may be more effective through the learning of those with the 'lived experience' (Glasby and Beresford, 2006; Repper and Breeze, 2007; Terry, 2012; Blackhall and Shafer, 2012). Indeed, this has become recognised as a way forward by professional bodies such as the Nursing and Midwifery Council (NMC, 2010).

6.2.3 Contributions to Practice

It is particularly important in line with legislative directives that anti-stigma pedagogy is introduced across all sectors including schools to ensure the public health agenda is achieved (JCPMH, 2013). Therefore, a

recommendation for practice relates to childhood emotional distress and the importance of early recognition and support as the way forward to prevent chronicity of both physical and emotional health in later life (Marmot, 2010; DoH, 2012). The Department of Education have pledged significant funds and service development for this very purpose. Within the current UK policy context, the mental health of children and young people would appear to be priority for this Government (Department for Education (DfE), 2016; 2017; PHE, 2015). They pledge a commitment to working with other organisations to deliver a programme of transformation over the next five years through investment to ensure that access to mental health service provision is available. Some of this vision is focussed on training teachers to be able to recognise mental distress (HM, 2017).

The importance of education on mental health sees schools as a priority setting, particularly as research would suggest a rising incidence of mental health problems in young people (Mulloy and Weist, 2013). There appears to be a clear commitment from partner organisations to adopt a whole systems approach (PHE, 2015). I would suggest perceptions are more resistant to change as we age. Mindful of this sustained effort targeting schools where 'meaning perspectives' are first formed is needed. Indeed, greater understanding may be gained from targeting non-healthcare undergraduates as well other educational contexts. With any policy driven change come tensions, however, within this space may be a place for creativity (Fawcett and Karban, 2005).

Whilst the above have their significance within an overall holistic care package, those with specific and complex issues require targeted and sustained support. Reflecting now on these issues it feels like I was not heard. Despite finally sharing the secret within a professional medical setting it was merely dismissed as 'food faddism' – was this because eating disorders were not fully understood at this time? Arguably we have moved on as research has offered new insights, this point is both contentious and contradictory as recent studies reveal troublesome results relating to heightened negative attitudes towards eating disorders (Bannatyne and Stapleton, 2015). So, one has to question have services improved? Only recently a parent whose daughter could not get help for her eating disorder had to travel a considerable distance away from the family home for treatment (Ford, 2016). The fact remains that 21st century mental health services are woefully inadequate (particularly so for young people with eating disorders).

6.2.4 Recommendations for Research

It would appear, there is space for further research that considers the impact of learning from an academic with lived experience. Praxis that is not based on power dynamics or authoritarian and oppressive forces. This other praxis as asserted by Gramsci will challenge the status quo and have the capability to be used in a more politically orientated way. This understanding of praxis brings together both theory and the practice in a more egalitarian way (Gitlin, Siegal and Boru, 1993 p.204).

Another recommendation is that this research can be used to encourage professional debate on the use of an academic with lived experience in anti- stigma pedagogy. Therefore, further lines of inquiry that focus on the synergy of both professional knowledge along with experience as a service user could be just as important as other forms of research. (Glasby and Beresford, 2006; Wallcraft, Shrank and Amering, 2009). Also, to conduct more narrative research that may connect to teaching (Banks and Banks, 2000) and open a space for a heuristic for raising awareness, compassion and a sense of hope (Crawford *et al*., 2013).

Furthermore, research into the perceptions of my students towards mental illness following the training (involving myself as academic with lived experience). Linking back to the literature review there would appear a need for ongoing studies of an exploratory nature in order to gain greater understanding of the mechanisms involved in changing attitudes towards mental health stigma (Bryne *et al*., 2013, Bizub and Davidson, 2011; O'Reilly Bell and Chen, 2012; Matteo 2013; Bharathy, Foo and Russell, 2016)

Dadds (2008) discusses some interesting insights that are relevant to further research, through the use of "empathic validity". In this context it applies to the 'potential' that 'practitioner research' through its different methods may influence and even act to transform people's emotional outlook and responses. This in turn may serve to create more empathic dispositions towards self and others. Empathic validity within practice focussed research may impact on the way learners interact; 'felt' learning.

To develop the qualities that are required within the 'caring' professions. Dadds (2008) is vehement and I would be inclined to agree, this should not be viewed in an inferior position to more traditional approaches to research.

Dadds (2008 p.280) discusses two sides to the consideration of this conceptualization. The first is referred to as 'internal empathetic validity' and relates to the extent to which the research changes the practitioner and potentially those involved. Secondly, there is 'external empathic validity' that has the capacity to have an impact on those with whom which it is then shared. As indicated it is anticipated this will be disseminated to my student audience within health, social care and public health and in so doing may potentially provide the site for further research.

Therefore, to reiterate workforce requires training on stigma and a need for the examination of attitudes towards mental health. The literature review highlighted some of the work already undertaken. This opportunity would now appear relevant within an emerging climate of change for mental health services. If the rhetoric which for a long time has not become reality is harnessed; with a vision to improve services then it has to start with attitudes, in a culture where these either are or become negative over a period of time. If focussing on interdisciplinary training then in line with the central pillars of Primary Health Care this requires wider collaborative partnerships. The pre-posed expansion of mental health services requires attention to staff attitudes and ongoing

support through supervision or mentoring to ensure a conducive work environment that not only promotes mutuality but also social capital (Brown, 2015; Brown, 2016).

The exposure of oppressive forces such as the ones discussed throughout this thesis may serve to heighten awareness of such dilemmas within the collective consciousness at the level of my students' learning. For example, the 'pseudo-medicalised identity' is one based on the evolving narrative that is constrained within the oppressive forces of 'specialist knowledge' as well as subjective opinionated epistemology. Stigma pedagogy is about changing people's frame of reference to how they perceive mental distress along with behaviour, as our attitudes affect the way we behave. At a time when mental health is a priority health topic it is of significant importance to develop curricula that embed lived experience and space to consider the stunted affect that this insidious phenomenon creates. In line with Maslow (1954), humans' development and ability to live a meaningful life is about having the conditions and opportunity to 'self-actualise'. The teaching and learning is an instrument to enable this actualising tendency (Boyd and Myers, 1988). My own existential angst was deeply entrenched within the institutional structures I had emerged from. The institution may therefore become a place of growth as opposed to the one that sought to hold me in check.

6.2.5 Summary of Recommendations

1. The anti-stigma learning tools to become an integral part of health, social care and public health undergraduate and post graduate curriculum.

2. Development of workshops and Continuing Professional Opportunities.

3. Extend the scope to include inter-professional learning opportunities that focus on the stories of lived experience of stigma.

4. To be offered as a training package for medical practitioners including psychiatrists.

5. Provision of robust mentoring systems and commitment to the promotion of workforce mental health and wellbeing promotion.

6. The development of a multi-agency learning programme that includes schools and colleges which target children's emotional health and wellbeing. With a particular focus on the stigma attached to eating disorders.

7. Further qualitative research through autoethnography on the lived experience of mental health stigma.

8. Additional research that extends the scope of this study, to measure the effects of such pedagogy as it translates in the practice setting.

6.3 The Challenges of My Disorientating Dilemma

From the outset of this doctoral journey, I have been implementing a highly reflexive gaze both inward and outward. The experience has had a twofold effect, firstly conferring a feeling that time had slowed down, suspended within a liminality where my awareness of every moment became magnified. Secondly, resulting in a self-consciousness that at times has been intense and somewhat overbearing in a realization of bifurcation to self-consciously move forward.

At the beginning of my deliberations, I came from the perspective that for me personally, the writing of an autoethnography on my stigma reality would not in any way be a therapeutic activity. However, as my thinking and opportunities for analytical reflexivity progressed, I started to become aware that it was very much providing remedial aspects (Custer, 2014). Perhaps the end stages of a transformative journey or "*voyage of vulnerability*" (Batchelor and Di Napoli, 2006 p.13), that was moving me beyond to be more authentic in the teaching and learning space.

There is a part of me that regressed to a level of 'being' that had many similarities to 'feelings' in previous moments of my life. Ones that at the time, I was not able to fully comprehend or understand. This affect is echoed by others who have highlighted the emotive impact of autoethnography, and of accessing memories as data. (Tillman-Healy, 1996; Struthers, 2012; Short, Turner and Grant, 2013; Frambach, 2015). If I were to liken this experience to

something, it would be what I anticipate an 'out of body experience' might feel like, yet the process and nature of inquiry is arguably an embodied one imbued with an "*ironic awareness*" of self as a "*social actor*" (Meneley and Young, 2005). There sits an interesting paradox as I feel as though I have stepped outside myself to analyse self in 'being' and 'practice', like looking at a mirror that reflects what has come before (Goldstein, 2002) and the connections to the wider whole, ones that are deeply intertwined with theory, historicity and the culture within which I am situated. Through the process I have moved through a perspective transformative cycle on my learning trajectory and have a conviction it will not be the last.

Finally due to the iterative qualities afforded to this inquiry, along with the anticipated extension into practice, it is difficult to conclude the process. Arguably this would not be of use with a storied thesis, one harnessing capacity to resonate in a dialogical learning space, to foster reflection on attitudes and opinions towards mental ill-health. Mindful of the above, there is opportunity to further extend this study through the consideration on how it translates to practice and further development of the findings which have been constrained here due to word limitations.

6.4 What Further Insights Have I Gained From This Research Endeavour?

I came to my doctoral studies with the full knowledge that I would do something related to mental health stigma. As a mental health practitioner, educator and as finally revealed a service user I am fully

committed to this endeavour and doing 'my bit' or so to speak to raise awareness amongst my students of the concerns stigma raises and the need to tackle these. I have seen first-hand that learning from lived experience is powerful pedagogy, a form that on evaluation my students have suggested they would like to engage with more.

I spent many months considering my methodology and was drawn to autoethnography. This genre appeared the right choice to address the questions and capture a transition of self, relative to the wider cultural and historical context (Bruner, 1990). It also enabled me to provide a 'voice' from a position of an academic with lived experience of mental distress. The uniting of both professional and personal experience has restored a balance, through assimilation and transformation in line with critical pedagogy. Arguably, this is one of the central aims of adopting autoethnography (Hayes and Fulton, 2015).

Likewise, an intriguing element of a quest, be it real or metaphorical is the opportunity exposed for chance encounters along the way. These have potential to create a field for the cultivation and a possible reframing of world views. I have been privileged to meet some inspirational characters throughout my professional career and more recently on this doctoral programme. However, the ones that stay with me with the greatest intensity are those with stories of adversity, survival, non-conformity and the celebration of difference.

One final thought- what can be gleaned from this series of stigma stories set within a bigger story? Indeed, it is just my lived experience. A stream of consciousness that is layered with memories of the past situated in the present. Well: I leave that to you the reader to decide. I have offered my interpretation of selected moments of my lived experience and it's saliency to my professional practice and the wider cultural context. I hope that the thesis reveals something of resonance to you the reader, which may be reflected upon around the issues of stigma and identity.

Thank you.

"we *cannot change our past, but we can change what our past means*"

(Sartre, 1955, in Cooney, 2000 p.147)

6.5 Epilogue

This epilogue serves to provide a reflective commentary in response to some of my viva questions and offer a concluding exploration of salient personal changes through my research journey. Firstly, in line with a function of both critical pedagogy and autoethnography, the process has been emancipatory, not only in stripping back the layers of my stigmatised identity, but also as a novice researcher grappling with an exciting and dynamic methodology. I have moved and continue to move beyond.

"*But what is this beyond, I ask myself"?*

"well…. a new found awareness, a bigger me, a renewed sense of vigour that I hope will continue to fuel further autoethnographic endeavours in both my research and teaching".

Another question posed in the viva was had the research led to any epiphanies? Indeed, I had not thought about a thesis framed in critical pedagogy in this light, as my aim was towards conscientization to praxis. However, this was an interesting point, one I have continued to ponder on post viva. I can see some parallels with both concepts and the interactional analysis and interpretation offered space for both liminal and epiphanic moments around some of the subtle and hidden webs of power that served to perpetuate my oppressive reality. One that continues to present a block for many living with mental ill- health. Thus, my 'epiphanies' were at times like a slap in the

face, waking me to a realisation and validation of long held feelings of unease. This gave rise to overwhelming anger that has now calmed and made way for a larger sense of self that now has the confidence to step into a shared learning space and tell my stories, to raise awareness of issues of *dissimilitude, disconnection, bifurcation, assimilation and transformation*. I have managed dissonance between unfolding moments of awareness and the need to balance my personal experience in a way that connects to the wider cultural context, and the extrapolation of this experience into more objective practice and research recommendations. This discordance has at times been painful, tiring and emotional. What I would describe as crippling frozen moments as I tried to make sense of the memories, the growing pains to transcend the shame and frame within an analytical story that makes temporal connections and captures resonant snap-shots in time.

I no longer feel a sense of difference or otherness, I feel more connected and my 'pseudo-medicalised identity' and 'other' selves have greeted one another, as I have gone back to go forward to become more whole both personally and professionally.

Having now come to the end of this journey, which undoubtedly feels like the beginnings of a new journey, I question:

"…what would I say to myself if I were to start again"?

Or

"…what advice would I offer to others about to embark on such a project?"

Well….on reflection,

"..I would say there are different approaches, don't be scared to be creative, be confident and review the possibilities.

To reiterate a quote from Ellis (2004 p.194) "*there is nothing more theoretical and analytical than a good story*".

Whilst, I believe my philosophical position remains unchanged, when undertaking future autoethnographical work, I will be compelled and have courage to write more evocatively. That said, I have enjoyed this sojourn to '*becoming*' comfortable with the autoethnographic method, along with developing creative writing skills, ones I did not think I possessed. Finally, I have unlocked a desire to develop and work on these new found interests.

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Appendix 1: Perspective Transformative Model (adapted from Mezirow 2000)

1. The disorientating dilemma	6. Planning a course of action
2. Self-Examination	7. Acquiring knowledge and skills necessary for acting on new meaning
3. Critical Assessment of assumptions	8. Trying on new roles provisionally
4. Recognition that the discontent and the process of transformation are shared	9. Building competence and self-confidence
5. Exploration of options	10. Reintegrating the new perspective into one's life

Appendix 2 Overview of Studies

(Adapted from Walker (2007) Accident and emergency staff opinion on the effects of family presence during adult resusciatation: critical literature review. *The Author: Journal Compilation.* p.335)

Author(s), year and country of origin	Design	Sampling strategy, total population and environment	Response Rate	Characteristics of respondents	Outcomes of education intervention on student attitudes	Critique
Altindag et al. (2006) Turkey	Quasi-experimental pre-post-test with control group. (1month follow-up)	?convenience sample comprising of medical students from two Universities in South Eastern Turkey	78% Study Group 77% Control Group	Undergraduate 1st year Medical Students Study group (n=25). (n=18 male) (n=7 female) Control group (n=35) (n=27 male) (n=8 female)	2 hour education on schizophrenia. Includes contact, viewing a film. Utilised 32 item attitudinal rating questionnaire. Post intervention attitude improvement and was still observed at 1 month follow up in intervention group. No significant change in control group.	Greater detail on sample of participants. Also a non-randomised sample which may impact on the generalizability of the study findings. Also lack of detail on the setting and the educational event. The procedures utilised for the analysis of data is not explicit and thus may interfere with internal validity.
Wood and Wahl (2006) USA	Experimental design, random assignment pre-post-test with control	? Convenience sample comprising of undergraduate students on psychology related topics	Not reported	Undergraduates in psychology subject area. (n=114) Experimental group (=57) Control group	Presentation consisting of video and interactive discussion involving mental health consumers. Significant increase in both knowledge and attitudinal scores.	No detail on sampling strategy provided. Lacks clarity and detail on the randomisation process for both groups, along with detail on the

	(no follow up)	1 University USA		(n=57) female (n=87) male (n=25) Did not report gender (n=2)		selection of sample which may impact on internal validity. Differences in group characteristics, more female.
Mann and Himelein (2008) USA	Experimental design with control, pre-post- test survey design. A follow up study occurred but with no control	?Convenience sample comprising of undergraduates at small public university	Not reported	Undergraduate Psychology Students on 2 Psychology classes **Sample 1** (n=53) Female (n=33) Male (n=20) **Sample 2** (n=48) Female (n=32) Male (n=16)	**Study 1** Statistically significant difference in pre-post scores indicating attitudes improved following the intervention in experimental group compared to control. **Study 2** Again less stigma post intervention.	Lacks detail on sampling strategy. No pilot study. Relatively small sample. Randomisation not described. Would have benefitted from greater detail regarding the validity and reliability of the measures used. Procedures employed in data analysis not addressed. Superficial account of results and analysis.
Roberts et al. (2008) UK	Randomised control trial	? convenience sample comprising of second year medical students	Not reported	Undergraduate medical students (n=332) Control (n= 182) Intervention (n=150) Female (n=214) Male (n=117) Did not specify gender (n=1)	Results showed no significant change in attitudes for either group. Thus the role play intervention had no impact. Some positive impact on stigma scores supporting previous research	Lacks detail on sampling strategy. Randomised trial not indicated in title, along with brief abstract. Lacks detail regarding randomisation procedure, which may impact on internal validity. Appears to be significant differences in group characteristics with more female participants. Slight temporal differences in the timing of the

						questionnaire. No statistical significance noted.
Bizub and Davidson (2011) USA	Qualitative inquiry	Purposive sample (although not specifically stated) from small private liberal arts college in the northeast	Not reported	Undergraduate Psychology students (n=5) all white; female (n=4) Male (n=1)	Compeer program, students befriended a person with lived experience of mental health. Findings suggest this form of contact was useful in providing students opportunity to consider and challenge their stigmatising perceptions	Small sample potentially limits transferability and generalizability of the findings beyond the study context. Limited detail regarding ethical processes. More detail on data collection. Limited discussion on saturation. Researchers limited examination of own role and importance of reflexivity not addressed, thus impacting on confirmability. No discussion of how they were recruited.
Galletly and Burton (2011) Australia	Pre & post intervention self-administered questionnaire	Not specific ? Convenience Final year medical students (during 6 week psychiatry rotation) at the University of Adelaide	Not reported	Medical students (n=87) Female (n=55)	Workshop comprising of contact and experimental elements. Results suggested a significant improvement in student's attitudes to people with the mental illness schizophrenia following the educational intervention.	Lacks a clear research question. Non-randomised sample may effect generalizability of the study. Total population not stated. No comparison group

Clement et al. (2012) UK	Experimental design 3 arm parallel groups, pragmatic randomised control trial Pre-post- test measure and (4 month follow –up)	Random sample assigned to groups, comprising of student nurses, University foundation year	100% at immediate post event 89% at 4 month interval	Nursing students (n=216). 360 initially consented to participate	Contact intervention DVD & live Lecture. No significant differences between DVD and live groups on some attitudinal scores. However, there were improvements with the combined social contact (DVD/Live)	Title identifies study as a randomised control trial. Greater detail on randomisation. Two attended wrong group, thus feedback was analysed according to group allocated at randomisation, authors acknowledged this limitation. Group characteristics mainly women, potential bias. Some differences in timing of sessions. 95% confidence limit. Statistical significance. Authors acknowledged need for qualitative inquiry.
Economou et al. (2012) Greece	Questionnaire survey Pre-post intervention following a 4 week clinical placement.	?Convenienc e sample Consisting of medical students at Greek University in 6th year of undergradua te medical training	98.8%	Medical students (n=160) approached. Participated (n=158) Analysed (n=155) men (n=78) women (n=77)	Psychiatric placement of 4 weeks duration in main psychiatric departments and psychiatric departments situated in a general hospital setting in Athens. There were elements of theory & practice, underpinned primarily by the bio-medical model. The placement did not appear to no influence on attitudes or they	Lacks detail on sampling and how recruited. Non-randomised sample may impact on the generalizability of the study results. Superficial account of the educational event and procedures. Response rate questionable as a further two participants were lost to follow-up. A brief account of the placement.

					appeared to become more negative	
O'Reilly, Bell and Chen (2012) Australia	Qualitative inquiry using focus groups and semi-structured interview guides five focus groups	Purposive sampling 11 undergraduate students 12 mental health consumer educators	Not reported	In 2008 all third year undergraduate pharmacy students n =258 participated in one of ten sessions. These students were then invited to participate in focus group 6-8 weeks following the sessions. 11 students chose to participate, along with (n=12) mental health consumer educators. Majority were female. Mean age 21	Consumer led educational sessions. Students reported decreased stigma, improved attitudes and behaviour changes in their professional practice.	Greater detail on the appropriateness of the design, recruitment strategy, particularly the small sample following initial group education. Limited detail given of the relationship between researcher and participants. Lacks specific detail on ethical procedures e.g. confidentiality and informed consent, which may impact on dependability and confirm ability. Lacks detail on data analysis procedure and how the themes were arrived at. No discussion of saturation. Researcher reflexivity not addressed, thus potential for impact on confirmability.
Bryne et al (2013) Australia	Qualitative inquiry using focus groups Exploratory design	Purposive sample with a cohort of undergraduate nursing students taking a	Not reported	From 23 students who undertook the training Nursing students (n=12) took part in the	Recovery module delivered by an academic with lived experience of mental health	Small scale study. Greater detail relating to the choice of research design. Did not explain in-depth why the participants were the most appropriate. Did not state why some

		major in mental health at an Australian university		interviews		learners (n = 11) chose not to participate. . No mention of data saturation. Not presented data from all. Greater detail of ethical issues e.g. confidentiality or debriefing participants after study. No examination of researchers own role, which may impact on credibility and confirmability. Innovative study and suggests transferability to other student groups.
Fredrich et al. (2013) UK	Experimental design pre-post-test questionnaires with control group (6 month follow-up)	? Convenience sample, comprising of medical students at four medical schools in different parts of England	Not reported	1452 Medical students Intervention group (n = 1066) Control group (n = 386)	Short lecture-key facts on stigma and discrimination. Narratives of lived experience and role-play activity. An improvement in all measures in both groups. At immediate follow-up significant improvement in stigma related attitudes relative to control group. At 6 months only 1 attitude item remained improved	Lacks detail and clarity on research design, ethical and data analysis procedure, with may interfere with overall validity and reliability.
Matteo	Qualitative	Convenience	Not	Undergraduate	Education	Total population not

(2013)USA	inquiry Pre-post- test assessment	sample and randomly assigned to intervention conditions comprising of psychology students in three introductory psychology classes from a small Catholic liberal arts college, Northeast USA	reported	psychology students (n = 69) women (n=41) men (n=28)	Video Contact using social distance measures post- test changes in empathic responses the majority in video and contact groups, which is deemed as important component for change in attitudes to occurs	stated. Do not make it explicit as to why the particular methods were used. Greater justification for choice of participants. Not made clear if any students chose not to participate. Greater detail of data collection procedure, only minimal data. No discussion of saturation. Researcher reflexivity not evident may impact on dependability and confirmability. Ethical issues. Superficial account of results. Provides some depth of data that strengthens credibility.
Kassam et al. (2013) Canada	Randomised control trial adopting a cluster randomization design Data collected 4 time points, before course, prior to course, after randomization, post intervention and 3-month follow-up.	Random sample consisting of medical students at a Canadian University	Baseline survey response rate 62% (n=111) of these 81% (n=90) completed second survey 86.5% (n=96) completed third survey 52.1%	Medical students undergraduate medical education eligible (n=179)	Contact- based educational interventions, delivered at two points in time. Stigma scores were significantly reduced post intervention, put no significant change following one time contact based session.	Identified as a randomised trial in title. Clear abstract along with objectives. Modifications made to study. Gender and cultural differences. These issues may impact on transferability & generalizability. Statistical significance noted

			(n=50) 3-month follow-up.			
Happell et al. (2014) Australia	Cohort study, pre-post intervention repeated measures (self-reported questionnaires) involving comparative analysis of attitude change	? Convenience sample consisting of nursing from 1 regional Australian University	Not reported	Nursing students 2 groups Cohort 1 (n = 70) Cohort 2 (n = 131)	Two groups one receiving a traditional bio-medically orientated mental health course Group 2 studied on a course delivered by an academic with lived experience. The course delivered by an academic with lived experience demonstrated statistically significant decrease in negative stereotypes which did not occur in the traditional course	Lacks clarity on sample. Uneven sample sizes. Differences in the timing of the educational event for the two groups, which may affect internal validity. Questionnaire not piloted.
Poreddi et al. (2015) India	A cross-sectional descriptive study.	Convenience sampling of 1st and 2nd year medical students and final year students.	91.1%	Medical Students 2 groups Cohort 1 65.4% (n = 115) 1st and 2nd year students. 69.3% were female Cohort 2(n =61) Final year students	Two groups, group 1 exposed to psychiatry training and group 2 not. Results indicate a more positive change in attitudes after exposure to psychiatry training than those who were not. But attitudes of discrimination do not change. There is an	Lacks detail on setting and educational event. Differences in groups characteristics. More women participated than men, potential bias. Small sample may impact on generalisability. Not clear whether questionnaire was piloted.

					urgent need to review training.	
Bannatyne and Stapleton (2015) Australia	Experimental design pre-post-test questionnaires Biogenetic intervention vs multifactorial intervention with control group (8 week follow-up)	Purposive sample, randomly assigned 40 fourth-year medical students	Not reported	Medical Students the final sample involved 40 4th year students aged 20-55. 60% (n = 24) were male. 40% (n =16) female. 20 participant identified Caucasian 14 Asian 6 'Other' 14 Medical Students Male = 6 Female = 8 Age 23-25	Results indicate both intervention groups had a reduced volitional stigma score in comparison to control group where there was not change in attitudes. These were also maintained at follow-up. Specific focus on Anorexia Nervosa.	Randomised design not evident in title. Small sample. All medical students from same university making generalizability more difficult.
Bharathy, Foo and Russell (2016) Malaysia	Audio-taped focus group interview Pre-determined questions	Purposive sample 14 medical student participants within college setting.	Not reported	14 medical students Male = 6 Female = 8 Age 23-25	Students took part in a focus group following an 8-week placement in psychiatry within an NGO providing services to those with mental illness and their carers. Results indicated that by having contact with	Small scale study Greater detail relating to the choice of research design. Did not explain in-depth why the participants were the most appropriate. No mention of data saturation. Greater detail of ethical issues e.g. confidentiality or debriefing participants

					service users appeared to lessen stigma	after study. Limited examination of researchers own role, which may impact on credibility and confirmability.
Burns et al. (2017) Australia	Randomised control trail Online self-report questionnaires at 3 intervals. Baseline (1 week prior to intervention) Post-intervention Further post intervention 2 months later.	Random sample consisting of nursing students from an Australian university.	Baseline Intervention group (n = 59) Post-intervention (n = 52) 2 months on (n = 50) Control group Baseline (n = 81) Post – intervention (n = 69) 2 months on (n = 59)	First year nursing students. (n =181) Intervention group (n =92) Control group (n = 89)	Intervention group received specific Mental Health First Aid training, by accredited professionals. The control group received no training during the timescales for data collection. The appeared to be a more positive view of mental illness from those in the intervention group receiving the training. This increase continued at the post intervention stage.	Identified as a randomised trial in title. Clear abstract along with objectives. Gender differences potential bias. These issues may impact on transferability & generalizability. Statistical significance noted. High drop- out rate in intervention group.

Muzyk et al. (2017) USA	Experimental design Questionnaire Pre and Post intervention.	Purposive sample consisting of pharmacy students in USA university.	71.2%	Third year pharmacy students The A Q-27 questionnaire (validated)	Module consisted of six classes. Pre-module questionnaire done online followed by post module questionnaire at the end of the last session. Mixed results with some positive changes in certain areas.	Non-randomised sample may effect generalizability of the study. No control group Total population not stated.

Appendix 3 Tolich (2010) Ten Foundational Guidelines for Autoethnographers.

Consent

1. Respect participants' autonomy and the voluntary nature of participation, and document the informed consent processes that are foundational to qualitative inquiry (Congress of Qualitative Inquiry, 2007).
2. Practice "process consent," checking at each stage to make sure participants still want to be part of the project (Ellis, 2007).
3. Recognize the conflict of interest or coercive influence when seeking informed consent after writing the manuscript (see Jago, 2002; Rambo, 2007).

Consultation

4. Consult with others, like an IRB (Chang, 2008; Congress of Qualitative Inquiry).

5. Autoethnographers should not publish anything they would not show the persons mentioned in the text (Medford, 2006).

Vulnerability

6. Beware of internal confidentiality: the relationship at risk is not with the researcher exposing confidences to outsiders, but confidences exposed among the participants or family members themselves (Tolich, 2004).

7. Treat any autoethnography as an inked tattoo by anticipating the author's future vulnerability.

8. Photovoice anticipatory ethics claims that no photo is worth harming others. In a similar way, no story should harm others, and if harm is unavoidable, take steps to minimize harm.

9. Those unable to minimize risk to self or others should use a nom de plume (Morse, 2002) as the default.

10. Assume all people mentioned in the text will read it one day (see Ellis, 1995a).

Source: Tolich M (2010) A Critique of Current Practice: Ten Foundational Guidelines for Autoethnographers. *Qualitative Health Research*. 20 (12) 1599-161

Appendix 4 Ethical Approval Letter

22nd June 2016

Lucy Pursehouse (Supervisor Debra Cureton)
University of Wolverhampton
FEHW

Dear Lucy Pursehouse (Debra Cureton)

Re: Growing Pains to Growing Shame and Beyond: A Reflexive Dyadic on Stigmatized Identity (An Autoethnography) Submitted to the Faculty of Education, Health and Wellbeing Ethics Sub-Committee Board (Health Professions, Psychology & Social Care)

Upon review by the Chair of the Ethics Committee your re-submitted Ethics Proposal was passed and given full approval (**Code 1 - Pass**). You are free to continue with your study. We would like to wish you every success with the project.

Yours sincerely

H Paniagua
Dr. H. Paniagua PhD, MSc, BSc (Hons) Cert. Ed. RN RM
Chair – School Ethics Committee

Richard Darby
Dr Richard Darby PhD, BSc
Chair – Ethics Panel

Appendix 5: Letter for participants

Dear …….

I am writing to invite you to participate in a research project, which I am conducting as part of a Professional Doctorate course in Health and Wellbeing at the University of Wolverhampton. I enclose an information sheet, which explains the title and aims of the project and what taking part will involve.

If you are willing to be interviewed, the interview will take approximately 45mins to 1hour. Anything you say would be totally confidential and any notes made as a result of the interview would be destroyed afterwards.

The interviews will take place at a location to suit you, and at a time that is convenient to yourself. A report will be written of the findings and numbers will replace all names so that you cannot be identified.

The information and data from the study will be retained for two years. All data will be stored in a locked filing cabinet, and electronic data will be password protected and stored on a password protected computer.

If you would prefer not to be involved, please destroy this letter. If you decide not to be involved I would like to assure you that you will not be affected in any way.

.

Yours sincerely,

Signed

Appendix 6: Participant Information Sheet

Growing Pains to Growing Shame and Beyond: *A reflexive dyadic on stigmatised identity.* (An Autoethnography)

The Project

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends / relatives. Please contact me with questions if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this

What is the purpose of this study?

The aims of this study are as follows:

1. Directed to the telling and sharing stories on the reality of stigma.
2. Using these stories to identify themes, allowing the researcher and audience to better understand this phenomenon.
3. Use this knowledge to develop others understanding of stigma
4. Provide recommendations to enhance anti-stigma educational programmes that draw on lived experiences of mental health stigma.

Why have I been chosen?

You have been invited to participate in this study as a result of your relationship to the researcher (Lucy Pursehouse).

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a

consent form. If you decide to take part you are still free to withdraw at any time[1] and without giving a reason.

What will happen if I decide to take part?

If you decide to participate you will be interviewed about your stories about mental health stigma as a relative of the researcher. The interview will be audio-recorded by the researcher. You will have opportunity to check content throughout the research process and provide comment on the researcher's interpretation of your experience.

Will it be confidential?

All the information about your participation in this study will be kept confidential. The transcription of the interview you participate in will be stored on a password protected computer in a locked office. Only the researcher working on the project will have access to the information. Your name will not appear in any publication.

What are the benefits of taking part?

The benefits for you if you take part, is having the opportunity to share stories and be part of the co-authoring process. There are no risks to you in taking part outside of those you would experience in everyday life. However, by taking part, you may remember things that you may find upsetting. If this occurs, the researcher will ask you if you want to continue to participate in the interview.

What will happen to the results of this research study?

The results will be part of a doctoral dissertation. Furthermore, this thesis will make recommendations for practice and provide guidance for educators involved in stigma pedagogy in mental health.

Who has reviewed the study?

The study has been reviewed by the University of Wolverhampton Faculty of Education, Health and Wellbeing Ethics Committee.

Contact for further information

Thank you for taking the time to read this information.

Appendix 7 Consent Form

CONSENT FORM

Title of Project:

Growing Pains to Growing Shame: *A reflexive dyadic on stigmatised identity.* (An Autoethnography)

Name of Researcher: Lucy Pursehouse

Please initial boxes

1. I confirm that I have read and understand the information sheet dated fo the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

3. I understand that my data will be stored securely and confidentially and that I will not be identifiable in any report or publication ☐

4. I understand that the researcher may wish to publish this study and any results found, for which I give my permission ☐

5. I agree for my interview to be tape recorded and for the data to be used for the purpose of this study. ☐

6. I agree to take part in the above study. ☐

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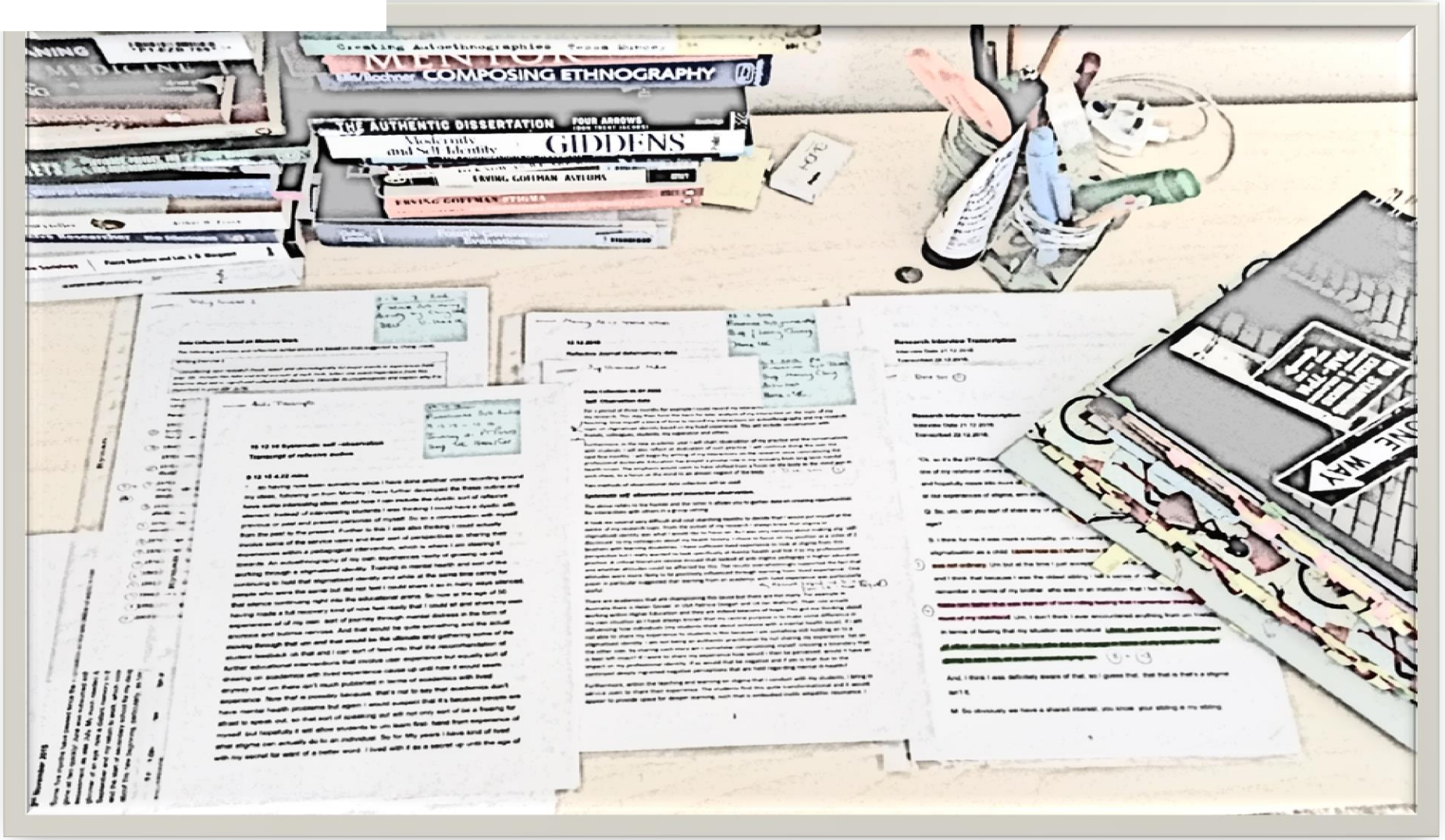
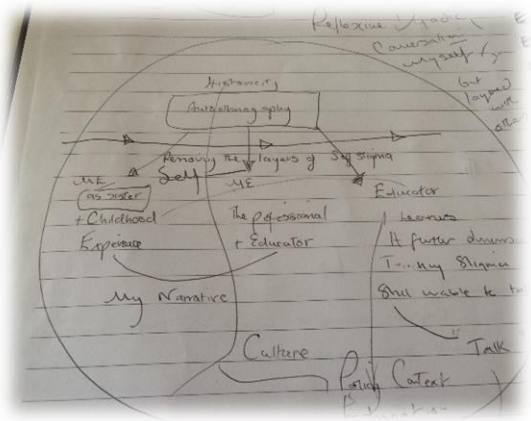
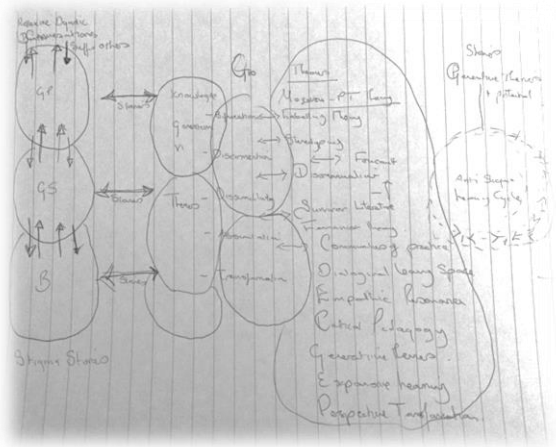
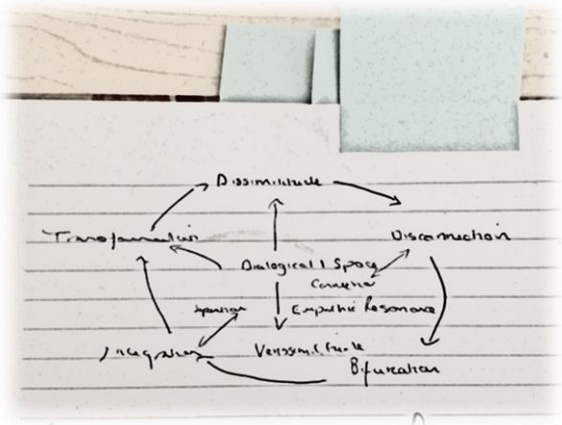
Appendix 8 Data Set Photos



Appendix 8 Data Set Photos

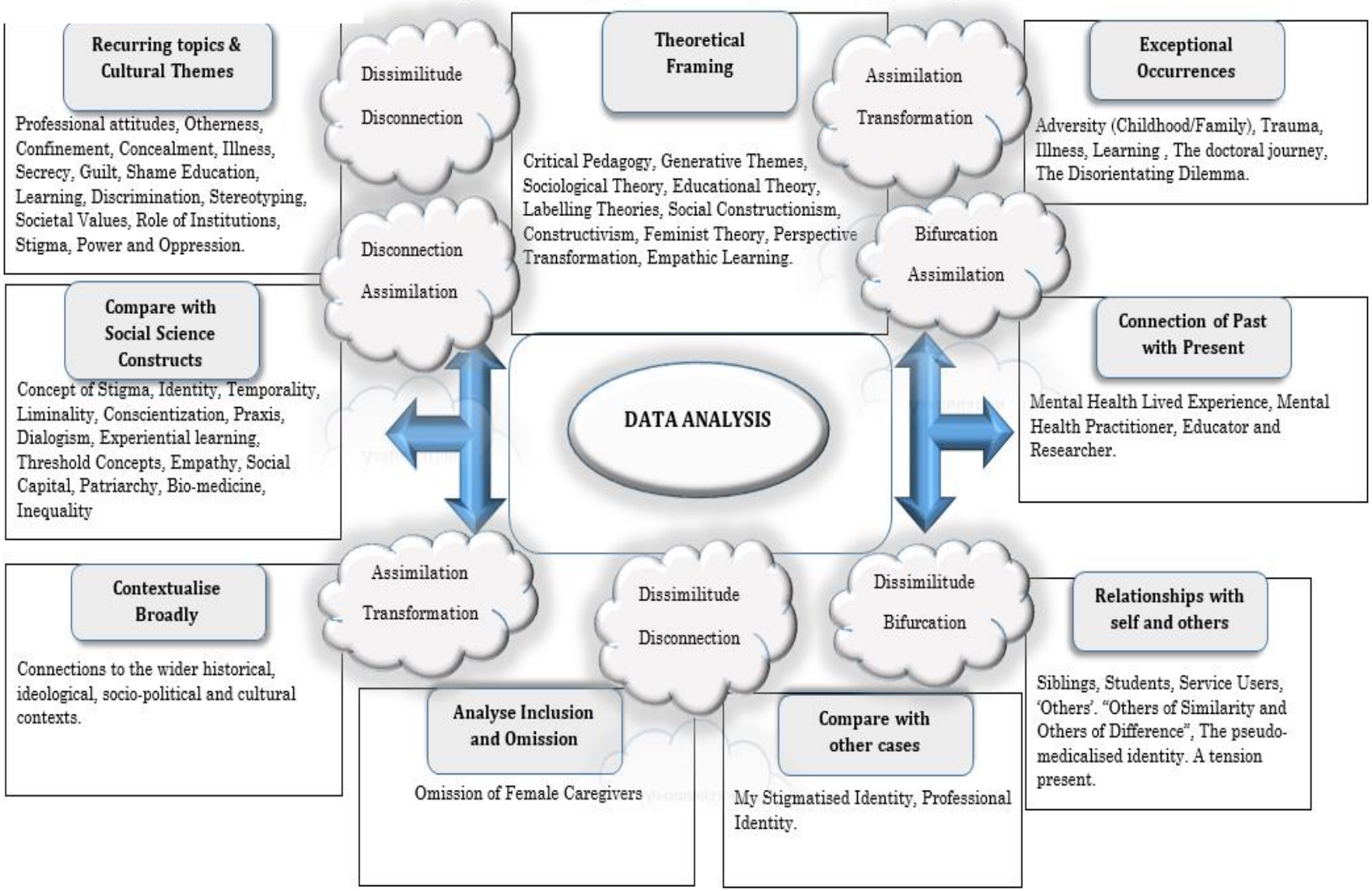






Appendix 9

Figure: Managing Data Analysis: Chang (2008)



Appendix 10 ***DATA SETS***	*Self-Observational Journal*	*Theme-board*	*Reflective Audios*	*Memory Work*	*Historical Records*	*Interview 1*	*Interview 2*
THEMES							
Dissimilitude	•			•	•	•	•
Disconnection	•	•		•	•	•	•
Bifurcation	•	•		•	•		
Integration & Assimilation	•	•	•			•	•
Transformation	•	•	•				

Adapted from Chang (2010) Salient Recurring Themes

Appendix 11 Conference Programme

10:00	**Opening** (Chancellor's Hall, Wulfruna Building) • Professor John Darling, Dean of Research • Dr Benjamin Halligan, Director of the Doctoral College	
	Group A (MA211)	Group B (MA213)
10:30 -10:45	**Dahiru Abdullahi (FSE)** Strategic framework for solar energy implementation in Nigeria	**Stuart Guy & Claire Dickens (FEHW)** "3 Minutes to Save a Life" - Deconstructing student emotional distress to mitigate the risk of suicide utilising compassion and hope.
10:50 - 11:10	**Aishat Bakre (FEHW)** Determinants of consumption of fish in older adults	**Leonard Love (FoA)** Building Bridges with Custard Pies: Subverting the regime of Shakespearean Performance
11:15 – 11:30	**Hussaini Bello (FSE)** Influence of molecular weight of Polyoxes™ on the release rate of model highly water soluble drug (diltiazem) from liquisolid formulation in comparison their counterpart physical mixture.	**Joanne Mills (FoA)** Engagement and Immersion: The extent to which an expanded narrative is present within American Minimalist Music during the 1960s and 1970s
11:35 – 11:50	**Ganna Borzenkova (FoA)** Designing Play Equipment for the Development of Social Competencies of Preschool Children with Cerebral Palsy	**Sara Smith (FSE)** Doing the portfolio – shifting the paradigm to support the development of capability?
11:55 – 12:10	**Isaac Danat (FEHW)** Risk factors for abnormal weight in older adults: a community-based cohort study in China	**Lucy Pursehouse (FEHW)** "Alternative Methodologies" and their use in Health and Social Care Research: Reflecting on the Challenges.
12:15 – 12:25	**Kyros Hadjisergis (FoSS)** Probation Officers' attitudes towards balancing public protection and human rights in the risk management framework of MAPPA.	**Robert Francis (FoA)** The Drift of the Creative Writer - Reading and Writing the Black Country
12:30 – 1:30	**Lunch & Networking** (Chancellor's Hall, Wulfruna Building)	
1:30 – 4:00	• **Poster Competition & Exhibition** (Chancellor's Hall) • **Doctoral Depictions Exhibition**	

Appendix 12 Seminar Information

Lectures and Seminars 2017-2018

This series of seminars and events spans education, health and wellbeing, bringing you a variety of engaging speakers and experts from the University of Wolverhampton and many other UK universities.

Date/Time	Title	Location
Wednesday 29th November 2017 1.00pm - 2.00pm	**Title: Ethical challenges in autoethnography: Paradigm pitfalls** The seminiar will discuss the ethical challenges involved in aut ethnographical research. There will be particular consideration to the notion of 'relational ethics' including the relationship of the researcher to the research. There will be a performative dialogue presenting some of the pitfalls from the researchers' experiences of gaining ethical approval as well as a discussion of the uniqueness of autoethnographical research and its subjectivity. Speaker: Lucy Pursehouse and Vik Kelly-Teare	Wolverhampton City Campus Room: MC225, Millennium City Building